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ABSTRACT

This proceedings reports on a forum which explored housing statistics for people with disabilities. An introduction identifies three broad areas of recommendations for consideration that arose from the forum: (1) a definition (and taxonomy) of housing that meets current and future profiles of where people actually live should be developed: (2) descriptive statistics on the housing characteristics of people living in the community and their service needs are required; and (3) research on the impact of housing on the health, well-being, and quality of life of individuals with disabilities should be undertaken. The next section offers highlights of individual presentations. The full texts are then presented for two panel discussions, a keynote speech (by Roberta Achtenberg, Senior Advisor to the Secretary of the Department of Housing and Urban Development), and reports from working groups. The first panel addressed the need for better data on housing for people with disabilities and the second panel considered the strengths and weaknesses of federal surveys. Two working groups also provided reports on disability housing statistics and policy needs for housing data. Also included are a list of participants and an appendix, "An Assessment of National Statistics on Supportive or Assisted Living for Those with Disability" (Robert Maynard and Robert Newcomer). (DB)

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NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH

FORUM 3

Disability Forum Report

Housing and Disability: Data Needs, Statistics and Policy

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Housing and Disability:
Data Needs, Statistics and Policy

Proceedings of the Third
National Disability Statistics and Policy Forum

May 13, 1996

Washington, D.C.

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CONTENTS

INTRODUCTION v
HIGHLIGHTS OF THE PRESENTATIONS vii

PANEL:
THE NEED FOR BETTER DATA ON HOUSING FOR PEOPLE WITH DISABILITIES
Thea Spires 1
Robyn Stone 4
Paul delVecchio 7
Speed Davis 11

PANEL:
FEDERAL SURVEYS—STRENGTHS AND WEAKNESSES
Sandra Newman 14
Duane McGough 19
Leonard Norry 22
Gerry Hendershot 24

KEYNOTE SPEAKER
Roberta Achtenberg 28

REPORTS FROM WORKING GROUPS
Disability Housing Statistics 31
Policy Needs for Housing Data 32

LIST OF PARTICIPANTS 34

APPENDIX
An Assessment of National Statistics on Supportive or Assisted Living for Those With Disability 37

INTRODUCTION

Mitchell P. LaPlante
Director, Disability Statistics Rehabilitation Research and Training Center

This Forum explores housing statistics and disability, an area of national social and health statistics that is generally wanting. It is fair to say that what we don't know and need to know greatly exceeds what we do know.

A most basic issue concerns how housing is defined. Statistics separate the U. S. population into two groups: the institutional population—those residing in health care institutions, including nursing homes, long-term hospitals and residential facilities for people with mental retardation or developmental disabilities, and other residential institutions, such as prisons—and the non-institutional population, including all residential households and some group-living situations with fewer than 10 residents. In large part, this division is a result of the logic of convenience—different data collection procedures are often needed to gather information on the characteristics of these populations. But it is a situation that has not kept pace with changing times, with de-institutionalization and an aging population.

Based on the 1990 Census, there are at least a million people who live in what we might call group homes, group facilities, or Board and Care facilities, and this is not an insignificant number. There are about 1.8 million people who live in nursing homes, which are what we might call total institutions.

At the same time, virtually all the national surveys that we use pertain to the non-institutional population and are generally based on interviews of people in households. This presents problems in disability research, since household surveys, as they are currently conducted, include some people who might actually be living in group homes, but we treat them as if they are ordinary households; in addition, we miss people who are living in the community in congregate living facilities that are not included in household surveys. Thus, a main weakness in our research lies in this gray area of classification of living arrangements and its interface with our survey efforts.

Once the definition of housing is addressed, the next issue concerns the content of information that is collected or that needs to be collected on housing and disability. Choice of housing is a paramount policy issue for people with disabilities. The majority of people in health care institutions have disabilities. However, we do not know how many have disabilities of such severity that they have no other alternative as to where they can live. For those who can and wish to live elsewhere, issues of informed choice, payment mechanisms and regulations, and supply and demand must be considered.

To describe the current situation and possible future scenarios, breakdowns of the populations in institutions and community housing by functional level and consumer preferences are needed, at a minimum. With continued de-institutionalization, more people fall into the gray area of intermediate housing that may be omitted in national sample surveys. For the population with disabilities living in households, there is a dearth of statistics on housing occupancy, ownership, and tenure. How many people with disabilities rent or own their apartments or single-family homes? How affordable is appropriate housing and how available is it? Is the home architecturally functional for people with disabilities? What home modifications are present and how were they paid for? How satisfied are consumers with their housing, and is it safe, comfortable, and private? These are questions that are hard to answer with the national statistics we have available.

Another issue concerns services and technologies needed by people with disabilities to live in their homes. It is unfortunate that housing structures and services are sometimes coupled, restricting consumers to fewer options than they would have if services could be provided independently of housing. For example, a person may be forced into an assisted living facility when services they would need to live at home are lacking. This may result from lack of supply, high cost, or restrictive public policies and regulations.

To better address this issue, statistics are needed on services and technologies provided in a variety of settings for people with similar levels of function. Statistics on services and assistive technologies used or needed by people with disabilities who reside in the community are especially needed. How many people with disabilities living in households utilize services and technologies and of what type, whether in their own homes or outside? Such services might be provided at Independent Living Centers or day care centers or at home by personal attendents. What is the amount of services or technology that is provided or needed, and how is it paid for? How does this compare with services and technologies provided in intermediate housing and institutions? Again, at a minimum, breakdowns by functional levels and preferences are needed. Furthermore, to what extent are services and technologies chosen freely and how satisfied are consumers with them?

Besides basic statistics on housing, it is important to acknowledge that housing itself has measurable impacts on mental, physical, and emotional health and well-being, a subject that is worthy of further research.

To summarize, at least three broad themes of recommendations arise from this Forum on housing and disability data:

1. A definition (and taxonomy) of housing that meets current and future profiles of where people actually live needs to be developed. The number of people living in housing that is intermediate between institutions and independent units in the community needs to be estimated and their living situations described. Modifications to national household surveys, or special surveys, must be developed to better enumerate the population living in intermediate housing.

2. Numerous descriptive statistics on the housing characteristics of people with disabilities living in the community and their service needs are required. These include ownership, type of housing, affordability, safety, and quality of housing. Services include both personal assistance and technologies that allow people with disabilities to live at home. There are programmatic requirements for some statistical data—HUD tracks over time the number of people with disabilities who have substantial housing needs. While many statistics can be obtained from data that have been collected, but have not been analyzed, additional efforts are required. Additional questions can be added to existing surveys in a cost effective way. To address the issue of people living in group quarters that are not large institutions, the scope of some sample surveys would need to be enlarged or new sampling efforts undertaken.

3. Research on the impact of housing on health, well-being, and quality of life should be undertaken and supported. While inadequate housing may have numerous negative impacts, the association of particularly effective types of housing with lower utilization and costs of health care and other services appears to be a particularly useful topic worthy of continued exploration. Research is needed that can document why people with disabilities have ended up in unsatisfactory housing and identify barriers to appropriate housing, as is continued research on consumer preferences and satisfaction generally. Research is needed on community attitudes toward people with disabilities and discrimination that may lead to segregation, and factors and practices that lead to successful integration need to be identified.

Many additional worthwhile ideas and recommendations were suggested during the Forum, so please read on. It is hoped that you will be challenged by the issues raised, and that new ways of approaching statistics on housing and disability will result.

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HIGHLIGHTS OF THE PRESENTATIONS

Thea Spires
National Action Coalition
for Disability Rights in Housing

If we are thinking about a certain type of housing, which is segregated housing only for people with disabilities, then we are looking at what we consider to be illegal; if it is truly housing that is segregated or diagnosis specific. If what is going on is legal—the segregation and the service linkage—then it is not housing, it is an institution. That is a very basic point and a very important point to us. (p. 1)

What is the critical point in what we know as people with disabilities about housing? It is when housing is studied, what is considered housing for us is very different from what is considered housing for people without disabilities. We know that and we are not happy about that. We are not happy that beds are counted as housing for people with disabilities. That is not housing for people without disabilities, and it is not good enough to be housing for us. If you are counting a bed, you are talking about an institution. If that is not good enough for housing for you, it is not good enough for me.

We want parity. We want equality. That's all. Just to be treated the same. That is all we are asking. We want services de-linked from our housing. (p. 2)

What don't we know? We don't know how many folks in those institutions want out. Oftentimes, what happens in the interview process that I have seen, certainly in HUD research, is that they go and they talk with the providers of the housing. They talk with the group home operators and say: "Are the people happy?" "Yes." "Can you give me a sample of somebody who could sit down and talk with me? I mean, somebody who can talk. We have to have someone with whom we can communicate."

That's a problem. We need researchers who are able to communicate with all people who are living in those situations, to have research materials in accessible formats and a procedure that is accessible and meaningful to people with a whole variety of communications skills. (p. 2)

Robyn Stone
Department of Health and Human Services

The issue for people with disabilities who do need services (and I would suggest that there are people living in the community who do need services) is that there are really two components: the housing piece and the service piece, which do need to be merged, particularly when we are thinking about how we are going to be spending our public dollars. (p. 4)

On the institutional side, we cover room, board, and services, while on the non-institutional side, we cover services only if we are lucky: if we have a Medicaid program that has a home- and community-based waiver that covers services and if we have state moneys that cover services and if we have local dollars that cover services. Otherwise, these are not covered. We need to decouple room and board from services, not because they shouldn't be linked, but because we need to have service dollars that follow the person and housing dollars that follow the person and that they should not be integrated for folks living in an institution and separated and bifurcated for people not living in an institution. (p. 4)

Paolo delVecchio
Department of Health and Human Services

With all due respect to Robyn and her positions, some of the consumer preference housing research that has gone on clearly shows that mental health consumers—and I am sure this is true for general disability folks as well—want our own housing. These Board and Care models, the kind of models involving congregate living situations and assisted living, are clearly not what we want. What we want is our own housing and our own apartments and our own houses to live in and not these kind of models which, as Thea mentioned, are oftentimes mini-institutions where our own independence is not put to the forefront. (p. 9)

These are the kinds of issues that I think need to be looked at closely: issues of independence, issues of re-institutionalization, and the whole

issue of consumer choice controlling self-determination. Oftentimes as consumers we are told where to live, and even the term 'placements" is used. We are not placements as objects to be placed, but we are people with choices. Oftentimes this is really ripe for coercive practices.

There is the whole issue again of service and housing de-linkage, and as consumers ourselves we want freedom from mandated services. We do not want the merger of housing and supports. One of the issues that we really get concerned about is this: With the advent of managed care and the privatization of health care delivery, we see more mandated housing models that come with the Board and Care and congregate-living model approaches. (p. 9)

Speed Davis
National Council on Disability

Probably the single most important thing we can do in housing is de-link services from housing. Once you do that, it allows you to look at housing as housing and to begin to wonder what type of housing people with disabilities are interested in having. Why are we not measuring home ownership for people with disabilities? Why are we not measuring the full range of options from condominiums to co-ops to communes to single family housing, and so on?

I have noticed that the discussion this morning and the information in the packet focuses on special housing—special housing with services. We need to break that mindset, so that we can talk about services when it is appropriate. Let's talk about housing. Thea made the very clear point that all of us receive some kind of services, but not all people with disabilities receive disability-related services. I don't. There is a large population of people with disabilities who live outside of the service-delivery model that we seem to be intent on measuring. (p. 11)

Sandra Newman
Johns Hopkins University

My analysis focused on one group of disabled adults—those 65 years of age and older—and I found, using these data, that roughly 17 percent of these households were living in housing units and neighborhoods that were very likely to either impede the efficient delivery of services in the home or to preclude their delivery altogether, whether because of the size of the home, the condition of the home, or the condition of the neighborhood. (p. 16)

We defined a representative group of elderly using the American Housing Survey and compared that group to a group of very impaired, elderly individuals from the Long-Term Care Survey. We defined impairment in terms of three or more ADLs or a cognitive impairment. We found very large differences, with the most impaired elderly having significantly higher rates of physical deficiencies in their dwellings and much higher rates of the absence of housing modifications that would be helpful, given their disabilities. (p. 16)

We found that living in decent, affordable housing and, when necessary, receiving supportive services, were associated with dramatic differences in mental health outcomes, in particular with much greater residential stability, reduced length of stay in hospital once an individual was hospitalized, and reduced need for additional services....

This work... seems to establish an initial empirical base for housing and mental health policies that acknowledge the contribution of adequate housing in a system of care for persons with mental illness. (p. 17)

Duane McGough
Department of Housing and Urban Development

Of all households in the American Housing Survey responding to the supplement, less than 10 percent reported any kind of difficulty. Less than 3 percent of all households had difficulty entering and exiting. Less than 4 percent of households reported difficulty going up and down steps inside the house. Only about 1 percent reported difficulty opening and closing doors or going through doors. Less than 2 percent had trouble reaching the bathroom facilities, using the sink, tub, shower, or toilet. Only about 1 and 1/2 percent reported difficulty moving between rooms. (p. 19)

Leonard Norry
U.S. Bureau of the Census

We have recently tabulated some data on the characteristics of housing units in California....

Renter households are more likely to have a householder with a disability than owner-occupied households, 10.6 to 8.5 percent. However, renter- and owner-occupied households are equally likely to have any member with a disability (14.7 and 14.4 percent).

We can also look at housing characteristics. Households with disabled members live in one-family detached houses 54.7 percent of the time, one-family attached 6.2 percent, 2–4 unit buildings 9.1 percent, larger apartment buildings 22.8 percent, and mobile homes 7.1 percent of the time. (p. 23)

Gerry Hendershot
National Center for Health Statistics

According to the 1990 HIS, only about 2.9 percent of all Americans—about 7 million people—lived in homes that had some kind of accommodation for persons with disabilities. The most common accessibility feature is handrails, found in about one-half of homes with any accessibility feature, followed by ramps (30 percent), extra wide doors (23 percent), and raised toilets (19 percent). (p. 25)

The 1994–95 Disability Followback Survey interviews are... being collected in 8 calendar periods or waves, and Wave 5 is now in the field.

Two questionnaires are being used: one for children and one for adults. In addition to other information about disability, both questionnaires obtain information about housing, including home-accessibility features like those in the 1990 survey; stairs in and into the home; and difficulty experienced in moving about the home. The adult questionnaire has additional information about housing, including questions about a person's past experience living in Board and Care facilities, assisted living facilities, and so on. (p. 25)

Roberta Achtenberg
Department of Housing and Urban Development

This year we developed a new methodology, and HUD's 1996 estimate of poor rental households headed by non-elderly disabled persons is 4.5 times higher than our previous estimates of persons with disability with worst-case housing needs. For the first time, we obtained access to SSI program audit data, and we were able to obtain more reliable counts on the number of SSI recipients who are non-elderly, disabled adults. And that is what led us to the current estimate, which is now 4.5 times the prior estimates.

These data indicate that 572,000 renter households are non-elderly, disabled, adult SSI recipients living alone. From the SSI audit data we were also able to determine that almost 1.6 million other renter households include a non-elderly disabled SSI recipient. But even this new estimate is a woeful undercount. (p. 28)

Together these data indicate that the incidence of priority housing problems is about 38 percent among poor non-elderly disabled adults who live alone and about 44 percent among those living in multi-member households. HUD's current best estimates indicate that at least 900,000 worst-case needs households include a non-elderly adult with a disability. And this is approximately 17 percent of the 5.3 million households with worst-case needs.

Without HUD's rental assistance programs, an even larger number of disabled people would face worst-case housing needs. HUD's rental assistance programs serve almost 570,000 households with non-elderly, disabled adult members; 344,000 non-elderly disabled adults who live alone receive HUD's rental assistance and another 222,000 receive HUD assistance as part of multi-member households....

Today's Forum focuses on data needs and statistics. I know you recognize that behind the numbers are human faces and very dramatic human needs, and I want to tell you a little bit about what HUD is trying to do now to address those very human needs. First, we have been redeploying our resources to create access for people with disabilities wherever possible. We are working closely with our Offices of Multi- and Single-Family Housing to educate them about their role in enforcing, of all things, the Federal Fair Housing Act.

Architects from these programs regularly review blueprints and construction to determine eligibility for HUD mortgage and insurance. From this point forward, these architects are also being instructed to review new constructions for

compliance with the Federal Fair Housing Act. In other words, we are telling builders that HUD money won't go to construction that isn't accessible to people with disabilities.

You might have thought that this was already being done. You are looking at me with eyes of astonishment. But I can tell you that only at the insistence of some of the advocates sitting in this very room, and when we brought on board somebody who truly understood and appreciated what this could mean, did we begin traveling down the right path. Quite frankly, this has happened as a result of hearing what the affected community is saying, opening our ears to the legitimate concerns and complaints of the advocacy community, developing numbers that are relatively sound numbers compared to the numbers that existed heretofore, and recognizing that HUD had a leadership obligation in this area and one that this secretary was willing to have HUD assume. (p. 29)

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PANEL:

THE NEED FOR BETTER DATA ON HOUSING FOR PEOPLE WITH DISABILITIES

Moderator: Jane West

Thea Spires
National Action Coalition for Disability Rights in Housing

The National Action Coalition is a new national organization. It is cross-disability. There are people from all across the country who are involved. It is a growing group and one of the first national groups made up of people with disabilities and advocates for people with disabilities regarding housing. The group has been meeting with Secretary Cisneros every other month to talk about housing policy and fair housing issues.

What do we at the National Action Coalition know about housing for people with disabilities? The first thing we know is, when we hear the term "housing for people with disabilities," we get nervous; and we think something is fishy about that. If somebody said, "housing for Hispanics," we would get nervous. If somebody said, "housing for African Americans," we would get nervous; "housing for Catholics," we would get nervous.

We are pretty nervous when they say housing for people with disabilities. It makes us think: oh, that is a certain kind of housing for just a certain kind of people. That is of great concern to us.

We don't hear very often or we haven't heard statistics regarding housing for people without disabilities. It is not characterized that way. It is not referred to in that way. And that is significant.

The point is that, when we are looking at this issue, if we are thinking about a certain type of housing, which is segregated housing only for people with disabilities, then we are looking at what we consider to be illegal; if it is truly housing that is segregated or diagnosis specific. If what is going on is legal—the segregation and the service linkage—then it is not housing, it is an institution. That is a very basic point and a very important point to us.

I did read the papers that were handed out about the group home issue and about assistive and supported housing. I tried to understand them in terms of where researchers were coming from.

But it kept occurring to me: Why are we trying to get real specific on what is a group quarters noninstitutional situation and a group quarters institutional situation without ten or more people? Maybe we are oversimplifying it, but to us in the coalition, it seems like if you have got segregated living arrangements with people with the same diagnosis or with all disabilities, that to be legal it has to be a medical facility. It is an institution or it is illegal housing.

We know that it is illegal to have segregation on the basis of race, color, creed, gender, status of disability. If there is segregation, it is illegal. We know that to have diagnosis-specific housing, even if it is on a certain floor or in a certain wing or in a certain area or in a certain neighborhood, we know that that is illegal, unless Congress has designated certain moneys to go toward certain particular projects for a particular diagnosis; and whether or not that would apply under Section 504 is not even in question. But generally speaking we know that if it is diagnosis-specific, it is illegal.

We know that if there are special terms and conditions imposed in housing, it is illegal: for example, you must need certain services to live here, you must use certain services to remain here, if you no longer need these services or if you need more services than what we offer, you need to leave.

The Fair Housing Act, Section 504, the ADA—any of these laws may apply in any given situation. If it is housing, the Fair Housing Act

always applies, and if there is state or local government money involved, the Title II of the ADA applies. And if it has federal money involved, Section 504 of the Rehabilitation Act applies. Each of those laws says, "Thou shalt not discriminate on the basis of disability," and has certain provisions, which say that, if you would establish special terms and conditions for people in housing on the basis of their disability, that is illegal.

Special terms and conditions are sometimes imposed upon people living in certain housing situations. For example, you must have a disability of alcoholism or substance abuse to live in this housing, or you may not drink alcohol on the premises or off the premises to continue to live in this housing, or you must go to AA every night to live in this housing. Now, that is either illegal housing or it is a treatment facility for people with the disability of alcoholism. It is one or the other in our minds. We will take it either way, but we believe that those situations are really treatment facilities. They should be seen as such.

There are enormous policy implications to everything that I am saying. We need to ask some questions: How much housing money is being spent on treatment facilities—not housing—that we think the Department of Health and Human Services should be involved with? Why are places like that considered housing for people like us and not for people without disabilities? Why are resources for "housing" going to treatment facilities instead of legitimate housing needs, money we feel should be going to help us buy our own homes like people without disabilities, to help us have an apartment in the community like people without disabilities, to live in a mobile home park if we so choose like people without disabilities?

What is the critical point in what we know as people with disabilities about housing? It is when housing is studied, what is considered housing for us is very different from what is considered housing for people without disabilities. We know that and we are not happy about that. We are not happy that beds are counted as housing for people with disabilities. That is not housing for people without disabilities, and it is not good enough to be housing for us. If you are counting a bed, you are talking about an institution. If that is not good enough for housing for you, it is not good enough for me.

We want parity. We want equality. That's all. Just to be treated the same. That is all we are asking. We want services de-linked from our housing. Housing for people with disabilities: why count me? I have a disability. I live in my home. I have a non-relative who provides me with meals. I don't cook; never have. I don't like to cook. That's okay.

And how come the person who has a cook and a butler and doesn't cook and is provided with housing by the person who is keeping him, why isn't that person considered in our definition as a group living situation as it was defined in here in my reading? It isn't equal. We aren't treated the same. We are treated differently. There is at least a double standard, if not a triple standard in some cases.

I guess that is my point, and I hope that we can talk in greater detail about the policy implications of these points.

What don't we know? We don't know how many folks in those institutions want out. Oftentimes, what happens in the interview process that I have seen, certainly in HUD research, is that they go and they talk with the providers of the housing. They talk with the group home operators and say: "Are the people happy?" "Yes." "Can you give me a sample of somebody who could sit down and talk with me? I mean, somebody who can talk. We have to have someone with whom we can communicate."

That's a problem. We need researchers who are able to communicate with all people who are living in those situations, to have research materials in accessible formats and a procedure that is accessible and that is meaningful to people with a whole variety of communications skills.

We also need to know some technical things about real housing. For example, we would like to know what building materials are not toxic. There are people who have sensitivities to toxic materials who cannot live in a lot of environments, and we would like to know and see more research in that area so that we could make recommendations for materials to be used in new construction and in renovations.

We don't care about diagnoses. You could say someone has cancer, and that tells you nothing about what their needs are in terms of activities of daily living. My mental illness, for example: Do you have any idea of what services I need? I could tell you C-4, C-5, compression. Does that tell you anything? Knowing a diagnosis is totally useless

when it comes to what kind of housing a person needs.

In my opinion, it is necessary to know only a few things when it comes to housing, and these are functional issues. You need to know whether the person has special mobility needs. That can be from any type of disability. You need to know if there is a sensitivity to toxic materials. That sensitivity may be psychological or physical. It doesn't matter what the diagnosis is. What matters is if there is a sensitivity. It is a functional matter.

When we talk about housing, we are talking about a physical, structural, real thing. We aren't talking about services. Services don't have anything to do with housing.

How many people have *no* services associated with their housing? Nobody. Is everyone a plumber? Is everyone an electrician, a dry cleaner? We all have some services. It depends on whether we are too busy to do our own cleaning, our own laundry. We don't know about plumbing. We don't know about electricity. We all need other people and some help with some things.

But does that affect where you live and your choices? Well, it doesn't affect ours either. It should not. Services should not be linked to housing. We don't need to know what a person's service needs are in order to figure out what kind of housing they need. One doesn't have anything to do with the other.

We would like to know which companies are making the most money from the current policies. All these group homes that are being built all over the place: Who is making the money on that? Who is meeting with HUD and talking with HUD to get the project-based policies to continue rather than person-based resources?

Why are there still project-based resources when HUD itself wrote a blueprint saying that the new HUD is going to devote itself to person-based services? We are moving everybody out of the awful public housing that is project-based. That's the problem in segregating low income residents. HUD says that the answer to this problem is that we are going to give all these people who live in public housing certificates so they can go live in an integrated manner out in the community.

That makes sense and that is fine. But for people with disabilities, we are going to continue to give those resources to the ARCs and to the Anchors and to the other organizations that build group homes, which are project-based.

Why did that happen? Why are the Fair Housing Act, Section 504, and the ADA not being enforced? And why does the Department of Health and Human Services support HUD's linkage of services with housing?

Those are the kinds of things that we don't know and that we certainly would like to know about, in addition to fair housing statistics.

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Robyn Stone
Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy
Office of the Assistant Secretary For Planning and Evaluation
Department of Health and Human Services.

Thea has raised some interesting and important issues around definition. My office and I have a different definition. It is an operational definition of housing that relates to the interface between Housing and Health and Human Services and public policy, namely, how are we going to be spending our public dollars?

Clearly, housing is a place where everybody resides, but there are public policy questions that are specifically related to certain issues, including the linkage between housing and services; and that is why my remarks are going to be related much more to those issues.

My office deals with the issues of long-term support for people with disabilities of all ages, from infancy to the grave. We take a very functional approach to disability. I was very pleased to hear Thea underscoring the need to focus on function as opposed to diseases and condition-specific issues, because, when we talk about housing and related services, we are talking about functional needs. I would suggest that not only physical functional need but also mental, cognitive functional needs need to be addressed from a residential as well as a service point of view.

My other definition of housing relates to long-term support and housing. There the focus is: What is the proper mix of housing and service support? And these are not just services in the sense of receiving something from another person. Services is defined in a much larger way, including home modifications, environmental changes, assistive technology, all of the technologies, both human and non-human, that allow people of all disabilities, ranging from minor to severe functional impairment to live in a residence.

The important thing for our office is that housing is often neglected. Health and Human Services focuses primarily on services and, frankly, primarily on health services, generally very disease-specific.

The issue for people with disabilities who do need services (and I would suggest that there are people living in the community who do need services) is that there are really two components: the housing piece and the service piece, which do need to be merged, particularly when we are thinking about how we are going to be spending our public dollars.

I'd like to mention some of the public policies that my office deals with. I really can't speak to HUD or to HCFA or to a lot of the other organizations in Health and Human Services.

We deal with issues that we think are particularly important as we move into the 21st century. First, how to think about developing a residential continuum, both for people who are disabled and for people who are not disabled, because people acquire some type of functional impairment at some point across their life span. We need to be thinking about housing that deals with those kinds of issues, housing that is flexible and housing that can employ the types of services, modifications, and assistive technologies that can deal with those changes across the life span. That is really the first and foremost issue that our office faces.

In addition to that, we are talking again about the "proper" mix of housing and supportive services across the life span and across disabilities. And what kind of home modifications and environmental changes and assistive technologies do we need to enhance that?

The second big question is: How do we finance residential alternatives? This is a particularly important question for low-income folks.

I come to this from an aging perspective. I have about 15 to 20 years of work in gerontology and aging, and much less of my time has been spent looking at people with disabilities across the life span. However, the point is that I believe that, after spending the past five years taking a more generic approach, that there are generic issues for folks with disabilities across the life span; and the questions that are raised with respect to elderly housing and supportive services also relate to the entire population.

That has to do with the fact that, on the institutional side, we cover room, board, and services, while on the non-institutional side, we cover services only if we are lucky: if we have a

Medicaid program that has a home- and community-based waiver that covers services and if we have state moneys that cover services and if we have local dollars that cover services. Otherwise, these are not covered. We need to decouple room and board from services, not because they shouldn't be linked, but because we need to have service dollars that follow the person and housing dollars that follow the person and they should not be integrated for folks living in an institution and separated and bifurcated for people not living in an institution. When I define an institution, I am basically talking about nursing homes, hospitals, ICFMRs. Clearly, that is not a perfect separation, and in fact that gets to my major point with respect to data: I do believe that it is important to be able to count.

I do believe that there are problems with the way the Census Bureau identifies quarters. When you end up with Census statistics, which we use for everything from calculating the CPI to looking at how we distribute our resources in this country, we end up not knowing who is living in institutions, who is living in the community, who is living in a single-family house, who is living in an apartment.

These days, when we look at the Census data we have absolutely no idea of what we are dealing with, because residential alternatives have changed dramatically. I believe we are going to see an even more tremendous change as we move into the 21st century. We have got to get a taxonomy of housing that is portraying what the real world looks like today. That is not to say that we use those data to segregate, but that we use those data so that we can inform public policy, which we currently cannot do because we don't have the data available.

Quality is another policy issue that our office is very much involved in. When we are talking about public dollars that are infused into a system, we have to deal with accountability and quality—quality for the consumers.

The whole question of regulation versus consumer direction is one that has emerged as a major point of concern, and that is: To what extent do we want to have a paper regulation process that focuses primarily on structure, process, and more and more on "outcomes"? I put 'outcomes' in quotes because we are in our infancy stages in terms of being able to develop outcome measures. How much do we want to invest in that kind of a strict regulatory process, versus relying much more heavily on consumer direction and consumer input? What is the role of the consumer, namely, the residents of any housing in which public dollars are invested?

And in the cases in which the consumer is not necessarily the person who can make those choices, what is the role of the family, friends, and others to inform the process about quality.

Also important is the quality of the environment, which has gotten very short shrift. I can give you an example of a high-quality assisted-living project in Oregon that has been touted to the hilt because of the home-like environment that it provides. However, a recent environmental review indicated that, even in the best of situations, the lighting was so poor and the sound was so poor that anyone with any type of cognitive impairment—not to mention physical impairment—would have tremendous difficulties in accessing and getting around there. Even though this place was home-like with a tremendous amount of consumer autonomy, the environmental design was very poor, which has major implications for a whole range of folks.

As far as the implications for data, I have already suggested that one of the problems is that we don't have an adequate taxonomy of what housing and services look like today and what they will look like in the 21st century. We lack good data bases, as the Newcomer and Maynard paper suggests. We lack data bases with sufficient information on health services. When I talk about health, I am not talking about specific diagnoses, but the very issues that Thea was raising, the need to focus much more on function, much more on needs, much more on sensitivities, much on environmental concerns, and get away from this mental health paradigm, because it is the needs paradigm that is going to affect what housing does or does not do for people.

I would suggest that we have made some inroads. We recently got the AHEAD study of the very old elderly, 75 and over, to include some questions about consumer choice and autonomy in housing, as well as some environmental questions. So we are beginning to make some movement. We have had some discussions with NCHS about putting new variables on the newest version of the Longitudinal Survey on Aging.

The problem is that we have probably got the best data on the elderly and tremendously poor data on the under-65 population, and even with the elderly we are very far from being where we

should be in capturing housing and services and those linkages. On the non-elderly side, it is possible that we may have some opportunity with the disability supplement to the NHIS, if we could ever get some money to do a follow-up. We are having enough trouble just getting the money to finish the survey first time around.

We've been talking with Marty Richie at the Census Bureau about doing something about the way that housing is defined. And we've been working with the large data bases at NCHS and in the Department of Health and Human Services to get better information on the residential side and better functional and environmental information so we can really understand what is happening to folks.

But I also think it is important that we should not focus only on national data bases. We have to do more targeted studies. I have two examples of the work we are doing in my office that suggests that we can put money into more targeted studies to get information on a whole range of housing and services.

The first is a Board and Care study that was recently completed by RTI and Brown. It was a study of 600 homes with interviews of operators, staff, and consumers, including consumers who had difficulty communicating. It looked at the role of regulation and consumer direction in providing the level of quality that folks really want in their housing and in their service linkages.

In addition, we have a second study that is currently under way, a national study of assisted living. Assisted living is primarily a private market venture right now, and we are doing this study, in part, because we want to get a sense of where the assisted living market is today. But we also want to inform policy in terms of how we can move assisted living in the direction of serving low-income and modest-income folks and in serving a range of people with disabilities. Again, this is a niche. This is not housing for everyone everywhere at all times, but it is a focus for public policy and one that I believe is warranted.

This is a two-tier data collection strategy. Our first is a screener of all self-identified assisted-living residents, in which we believe we will be able to develop a national probability sample. Then, we will be doing a detailed survey of 600 homes, again talking with operators, staff, and residents, as well as with the financial investors, to get a sense of what are the financial issues in developing an assisted-living market.

To conclude, I believe that the world is changing and that housing is important for quality of life and that we have to begin to capture living arrangements in a very different way than we are capturing them today.

There is a terrible lack of data, particularly in the area of housing characteristics and how they link with health and services data. There is a need for improvement in national data collection, and there is also a need for comparable work with a whole range of populations. We have put a lot of money into aging surveys. We need to put more and more dollars into surveys that are addressing people under the age of 65.

Sean Sweeney: Robyn, you didn't mention when these studies will be completed or what has been completed so far.

Robyn Stone: The Board and Care Study that was done by Research Triangle Institute has been completed and is available from our office.

The Assisted Living Study is still in the design stage, and we project that it will probably be completed toward the middle of 1997.

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Paolo delVecchio
Consumer Affairs Specialist
Center for Mental Health Services
Department of Health and Human Services

First of all, I am a mental health consumer or a psychiatric survivor. In the United States, as well as around the world, for the past 30 years there has been a growing movement of consumers—or individuals who call themselves survivors—to talk about issues of self-determination, self-help, rights protection, and so on.

I joined this consumer-survivor movement some 15 years ago, and the one issue that has really struck me is the stigma and discrimination that still persists against people labeled with a mental illness. We have often talked about being a hidden disability, and I will discuss this later when I get into some of the data issues and how this discrimination impacts upon our housing needs.

I am also a family member—all of my immediate family members also receive mental health services—as well as a provider—I have a Master's in social work with an emphasis on community organization and social planning.

As I mentioned, I have worked in consumer-operated self-help services, including housing programs operated by and for consumers. I have worked as a county bureaucrat in Philadelphia, as a mental health systems planner and program developer, meeting the needs of consumer-survivors who were experiencing homelessness, those affected by HIV/AIDS, as well as those who are long-term institutionalized an average of 25 years. I have also worked in housing policy development, supported housing, grant development, and so on.

I am a member of a national group called The Consumer Survivor Research and Policy Work Group. This organization is composed of mental health consumers who are researchers ourselves and are changing our role from simply being the subject of research to actually designing and operating our own research ourselves. I am also on the advisory group for the Mental Health Statistics Improvement Program. I am on the planning group for the 68th Annual National Mental Health Statistics Conference, that will be held at the end of May here in D.C. In my present job, I work in promoting consumer-survivor involvement in the federal agency where I work, and it is not an easy job.

I do want to issue a disclaimer: These are my personal views, the views of me as an individual within the consumer-survivor movement and not necessarily those of the Center For Mental Health Services.

The first question is: Why are better information and data needed? Clearly, I think data is an important aspect. There are significant gaps in our knowledge base as it relates to housing and disability. Just to quote one particular source in the federal task force on homelessness, a report published I believe in 1992, called "Outcasts on Main Street": there is a "paucity of information research on the housing needs and housing outcomes of persons with mental illness who are homeless." It is imperative that mental health and housing providers, consumers, and researchers focus attention on these issues.

The development of such an information base by the mental health community would help inform housing planners and developers in communities about housing needs for this target population. Additionally, it would assist consumers in choosing the most appropriate housing that they prefer.

So, clearly, there is a major need for data as it relates to housing, and I hope that researchers and policy makers will recognize the importance of the meaningful involvement of consumers ourselves in this research. Consumer-survivor involvement in all aspects of research and data issues is too often overlooked. If we are really looking at the policy issues that affect people, doesn't it make sense to ask the people ourselves to be involved in that research? Too often it is done to us or for us, rather than with us. I would strongly encourage you to really look at the kind of research that has been going on.

Again, why is data needed? First of all for me as an advocate, for advocacy purposes. Data and statistics are so important in decision making; from an advocate's perspective, having this kind of data available about what our housing needs actually are is vital.

As I talk to consumers from around the country in my job, the number one issue that people raise with me is housing. I guess housing is going to be a growing concern, with the very real reorganization of HUD and the consolidated planning and local control processes going on. There is going to be a real need for advocacy data around the housing needs of people with disabilities so that we can be at the table.

In 1994, HUD presented a report to Congress on worst-case needs for housing assistance. It stated that almost half of all very low income disabled people have worst-case needs. This particular report also mentioned that most folks who have disabilities often live in the most severely inadequate housing. Further in this report, HUD said that people often have multiple problems and needs and that nine-tenths of disabled people in the particular study are impoverished.

This kind of data is really important, again, for advocacy purposes. HUD further stated in this report that they intend to exploit this finding in greater detail. I don't know if anything has been done in that area. But clearly these are really important findings. How many people know about this particular data, however?

In the mental health arena, approximately one in five people will have a serious mental health illness during their lifetimes. Regarding homelessness, the data varies, but it has been stated that approximately one in three homeless people have mental illness. Approximately 200,000 people are living in our streets today. Clearly, there is a need for this kind of data for our advocacy purposes to ensure that we get our fair share of housing.

The second reason this kind of data is needed is public awareness. Again, the issue of stigmatization and discrimination is still so rampant in society. We pass laws like the Americans With Disabilities Act. We pass laws like the Fair Housing Act, but we continue to see the discrimination that people experience in trying to access their own housing. It is still so rampant, and people that I talk to across the country have been told that they can't live in the housing that they choose because of their own particular disability.

Again, the issues of community resistance and discrimination amongst those developing housing programs for folks with mental health problems: the NIMBY syndrome. This is still in existence. You see time and time again reports in the news of people's housing being firebombed, even.

This is the extent of the stigma and discrimination that we as mental health consumers and survivors still experience. Within the same federal document, "Outcasts on Main Street," they stated that "people with severe mental illnesses have a long history of being stigmatized, reviled, shunned, shut away," and in previous eras killed.

Clearly, this still translates into the discrimination that we experience not only in housing but in very many other areas in our life, such as employment and health care coverage. One of the issues that Congress is battling right now is parity for mental health coverage as it relates to health care coverage.

The third major reason that we need data, for me, as an advocate and as an organizer, is for consciousness raising and for organizing purposes in our own community. Many of us consumers-survivors don't have adequate information and knowledge of what the housing needs and issues are. This is the kind of data that can be a really important tool to help us pull together for our own advocacy and organizing purposes.

I also want to mention that the fourth issue regarding the need for housing data is around improving the amount of housing that is out there for people. As Robyn mentioned, there is a growing focus on outcomes-driven human services now. That is the talk of the day here in D.C. and across the country. What I would really encourage folks to look at are developing outcomes that are based, again, on consumer input, based on what consumers themselves are saying. The kind of outcomes we are really interested in seeing are issues of choice, voluntariness, issues of independence, outcomes around de-stigmatization, outcomes of recovery focus, outcomes of the self definition of our problems and our particular illnesses.

Another issue is consumer satisfaction and really measuring how satisfied we are with our particular living situations. And, perhaps more importantly, how dissatisfied we are with our particular housing situation. This kind of information can help in planning the kind of housing that we want, as well as improving the existing housing.

So, again, four major reasons why I think data

are needed: One is for advocacy purposes. The second is for public awareness. The third is our own consciousness raising, and fourth is around improving the existing housing stock.

I think we often talk about the values and philosophy of housing and the values and philosophy within the consumer movement, but really these kinds of values don't often get translated into data issues. I would encourage researchers to look at the issues related to independence, to look at how you can get some hard data and research on independence. I am referring to the issue of consumers having our own housing.

With all due respect to Robyn and her positions, some of the consumer preference housing research that has gone on clearly shows that mental health consumers—and I am sure this is true for general disability folks as well—want our own housing. These Board and Care models, the kind of models involving congregate living situations and assisted living, are clearly not what we want. What we want is our own housing and our own apartments and our own houses to live in and not these kind of models which, as Thea mentioned, are oftentimes mini-institutions where our own independence is not put to the forefront.

Also there is the large concern over this concept of a residential continuum of care. This is something that HUD has also been putting forth, the concept that a person moves to some sort of a transitional model to their own permanent model. This is oftentimes not what consumers want, and people often don't fit into a little box of moving from point A to point B. There is also the issue of continually moving in between these different housing models and what does that do to a person. Would you want to move every six months to a different housing model? So we have a lot of concerns about this continuum of care concept.

Many of us in the mental health and general disability movement and consumer movement have a major concern about re-institutionalization; and are we going to see within the next decade, as a reaction to de-institutionalization, more pushing people back into institutions. Will the new institutions of tomorrow and perhaps even today be jails and prisons? There have been some studies that have shown that one third of all folks in prisons and jails take psychotropic medications.

These are the kinds of issues that I think need to be looked at closely: issues of independence, issues of re-institutionalization, and the whole issue of consumer choice controlling self-determination. Oftentimes as consumers we are told where to live, and even the term 'placements' is used. We are not placements as objects to be placed, but we are people with choices. Oftentimes this is really ripe for coercive practices.

There is the whole issue again of service and housing de-linkage, and as consumers ourselves we want freedom from mandated services. We do not want the merger of housing and supports. One of the issues that we really get concerned about is this: With the advent of managed care and the privatization of health care delivery, we see more mandated housing models that come with the Board and Care and congregate-living model approaches.

I was encouraged to hear Robyn talk about moving away from a medical model perspective and moving more towards the environmental perspective; but, again, I think we need to keep housing and services separate; and that housing is a separate right that should not be linked to the kind of supports we receive. Supports should be received based on people's preferences, however, and I would encourage folks to look at the issue of preferences as it relates to supports and also look at the concept of peer supports, of consumers ourselves providing our own supports to our own peers.

Community integration is another area where data is needed, of non-segregation of housing, of ghettoization of housing. We need data to document the nature of where we live and where people want to live. There was a big issue a year or so ago regarding moving folks with psychiatric disabilities out of elderly housing that is supported by HUD. Clearly, we need to look at this from a policy perspective, and from a fair housing perspective as well.

Issues regarding safety, comfort, and privacy are basic housing issues. We need to measure these kinds of concepts. We need to measure affordability and availability in the cost of housing. A study that was done by the National Institute of Mental Health in 1989 said that the average income for mental health consumers was $4200 a year. Only 25 percent of us are employed and less than ten percent of us are employed outside of sheltered workshops.

Clearly, housing is an economic issue and we

can't forget this. There was a study done by the New York State Office of Mental Health, released in 1995, that said that in terms of looking at data and statistics as they relate to housing, we cannot overlook that housing is related to economic inequality and the accompanying stigmatization of certain social groups places outer limits around the choices of consumers, and we must look at these larger issues related to the economic needs of mental health consumers if we are going to look at the issue of housing as a whole.

To conclude, I'd like to get back to the issue of involving consumer-survivors in all aspects of research and data. This also is not only the right thing to do, but it increases the validity and meaningfulness of data. While I was waiting this morning, I was looking through some of the reports that were in the packet, and very little talks about involving the consumer in the research that is being done. I think that is a major thing that has been overlooked in some of this data.

We have to be involved in the research design of the questions that are to be asked. We have to be involved in the data collection and looking at the kind of instruments being developed, as well as collecting qualitative data and establishing the kind of rapport we can with our fellow consumers. We must be involved in the analysis of data that is collected. What does this data mean for us? We have to be involved in the dissemination of the data so that we are really spreading the word and the knowledge, really applying this knowledge.

I would like to bring your attention back to the National Action Coalition's paper of January 1994 debunking the myths. The number one issue that they put on Page 4 is that people with disabilities are the best and most reliable source of information about our housing and fair housing needs, and I would encourage you to follow their advice on that point.

Speed Davis
Executive Assistant to the Chairperson
National Council on Disability

The National Council on Disability is a federal agency. It is independent of all other agencies and has its own line item in the budget. The council consists of 15 otherwise private citizens who devote part of their time to duties of the Council. We do policy development research and make policy recommendations to the President and the Congress.

We have been quite involved in housing and anticipate being even more involved. We established housing last year as one of our top 6 priority areas in which to become active, and we have had a couple of meetings with Secretary Cisneros and have been very supportive of the National Action Coalition and their work with Cisneros. Our Chair, Marca Bristo, has attended at least one of the meetings that they have had. These are monthly meetings, and we continue to follow their efforts and support them very strongly.

We are also taking part in Habitat 2, a United Nations conference coming up next month, devoted to housing and community development around the world. We have been working very hard at the council to make sure the conference documents include the interests of people with disabilities. When we first found the documents several months ago, they were bereft of references to people with disabilities, other than as members of vulnerable groups. I am pleased to say that about 80 percent of the recommendations we have made have been incorporated into the document. We are still working on the other 20 percent.

One thing we've done to help us set an agenda was to hold a meeting two weeks ago: we pulled together about 300 people with disabilities from around the country who are knowledgeable in one of eleven different areas, including housing. We locked them up in a hotel for three days and asked them to give their best advice and help us develop some policy recommendations around each of the eleven topics. We will be publishing that report for the President and for the Congress and for public information by the end of July.

The Work Group on Housing came up with recommendations similar to those you heard from the National Action Coalition. Appropriately, they had heavy influence on that work group, and there are some very good recommendations.

The first is probably the single most important thing we can do in housing: de-linking services from housing. Once you do that, it allows you to look at housing as housing and to begin to wonder what type of housing people with disabilities are interested in having. Why are we not measuring home ownership for people with disabilities? Why are we not measuring the full range of options from condominiums to co-ops to communes to single family housing, and so on?

I have noticed that the discussion this morning and the information in the packet focuses on special housing—special housing with services. We need to break that mindset, so that we can talk about services when it is appropriate. Let's talk about housing. Thea made the very clear point that all of us receive some kind of services, but not all people with disabilities receive disability-related services. I don't. There is a large population of people with disabilities who live outside of the service-delivery model that we seem to be intent on measuring.

Secondly, we must end segregation and set-aside by doing away with disability-specific housing and housing for specific disabilities. We encourage strong enforcement of the Fair Housing Act, Section 504, and Title II of the ADA so that housing rights can be enforced.

Third, housing should be made more affordable for people with disabilities. This is not a disability-related issue, but an income-related issue. Generic, income-related housing programs that are designed to make housing more affordable should include people with disabilities. We don't need separate programs.

The fourth recommendation: home ownership programs. Why can't vouchers be used for home ownership as well as for rental? People with disabilities have the same interest in owning property as everybody else does.

Number five is fairly basic. It is that all housing be made structurally accessible. The amendments to the Fair Housing Act of 1988 contain a basic accessibility requirement for multi-family housing, which is not full accessibility. We need to have the basic space necessary, wide

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enough doorways, and certain other structural enhancements that are very low cost if done in initial construction, in order to allow a living unit, whether it is an apartment or a house, to be modified to meet the individual needs of the resident of that unit with a minimum of cost and a minimum of structural change.

This not only enhances the ability of people with disabilities to live in a building in a particular time. It moves toward what we are calling universal design. It is moving toward a housing model—a physical housing model—that allows a person to stay in the unit as long as they want to as their needs change over time. All of us in our lifetimes move from a state of complete helplessness at infancy through various levels of independence and self sufficiency, and then as we wind down at the end of our lives, we move toward more and more dependence again.

If we make housing physically usable and accessible and modifiable, then we reduce the number of times a person has to move based on their physical needs. Maybe we can do away with people having to move back and forth as their life changes over time.

The work group's sixth recommendation: There needs to be more construction of two- and three-bedroom accessible units. If my previous point is adopted, this is an issue that goes away. Right now, what we are doing is this: Except for multi-family housing, current policies are that there be a percentage set aside for fully accessible housing. Most often that ends up being a one-bedroom unit, which does not allow for a person who has a personal assistant. It does not allow for a person who prefers to live with a roommate for whatever reason.

In Massachusetts, where I lived for a number of years, they have taken care of that. Their accessibility code requires five percent in both the public and private sectors, and it requires that five percent be proportionally spread among projects and within particular projects. If they have two- and three-bedroom units, then some percentage of those accessible units also have to be two- and three-bedroom units. That way people can have families. What a concept: people with disabilities having families. It happens.

Those are the basic recommendations that came out of that work session. When we publish the final report, there will be some more detail and some additional recommendations.

Some of the concepts that I wanted to emphasize today, we have already talked about. One of those is group homes as institutions. Most people with disabilities look at group homes as simply smaller institutions. We hope that, as public policy develops, we will move away from even group homes as a concept. We can do this if we de-link housing from services. We keep coming back to that concept.

Services should follow the person wherever that person chooses to live. A person's service needs may change over time. As Paolo said, we don't want to have to make that person keep moving from housing model to housing model, as their needs change. Let's find them a place that meets their needs, whether it is ownership or rental or some other form, and let's bring the services to them.

I think an important point that Paolo brushed upon and moved toward is that, particularly when we are talking about the current models of service-based housing, most people with disabilities living in those housing models are not there by choice. They are there because the funding source has said, "This is where you are going to be." We need to start looking at what people's choices are and finding ways to get them there as a matter of public policy.

What are our data needs? We need data for accountability. We have in law a number of rights, a number of requirements, and we need data to make sure that there is accountability, and we need to go beyond just measuring complaints. Complaints get bureaucratized to death. They don't get us where we need to go.

I am a strong believer that what you measure is what you get, and if we evaluate housing providers based on their mandate to provide nondiscriminatory housing, then we will get more nondiscriminatory housing. We need data that compares the living situations of people with disabilities to the living situations of people without disabilities, so that we can measure the movement toward the convergence of those two types of numbers.

We need data to measure the effectiveness of policy and policy changes. It appears that we are about to go through a major change at HUD, as the House has passed legislation which has now gone into conference committee, that will substantially change the Federal Government's involvement in housing. We are going to need to establish data streams to measure the effect of those changes on people with disabilities and

their ability to meet their own housing goals.

We need data that shows us the different effects of policies on minorities. We know anecdotally and from conventional wisdom that minorities are not benefiting nearly to the extent that non-minorities are benefiting from housing policy. We need to be able to track that and make policy changes and strategic changes and tactical changes to bring convergence.

Again, the important point is to come around to persons with disabilities and what they want and make housing and services separate. We can talk about services some other day, but we are here today to talk about housing.

Jane West: I would just like to make one observation. One of the messages I take from this session is that what gets measured gets attention. If we have good numbers about whatever the topic is, that is going to galvanize people and people's attention.

I think that data is very powerful in shaping policy in that way, and if we spend all of our focus on gathering information about group homes, for example, that is going to really shape a lot of what the policy discussion is about.

PANEL:

FEDERAL SURVEYS—STRENGTHS AND WEAKNESSES

Moderator: Robert Newcomer

Sandra Newman
Associate Director, Institute for Policy Studies
Johns Hopkins University

As someone who has spent more than 20 years trying to convince anyone who will listen to me about the importance of doing careful research on the housing environment in which disabled populations reside, I am really both delighted and gratified that this conference is taking place. Unfortunately, the amount of systematic and rigorous analysis of housing issues pertaining to disabled populations is extremely modest. Every time I write a paper on one or another aspect of this issue, I am always astounded at how brief the literature review section of the paper is.

So for all intents and purposes, I would say that we are dealing with largely uncharted territory. While there are obviously risks associated with moving into any new area where very little is known, I think it is also very exciting and challenging to focus on a topic with more gaps than knowledge, in which we can make contributions not at the margin but in much larger increments. That is how I would describe this field.

I would like to touch on three topics: First, some alternative ways in which we might conceptualize the role of housing. As every researcher knows, it is very important to have a conceptual framework to organize and to guide one's research.

Second, a very brief overview of what we have learned about housing for disabled populations. Much of what we have learned has been based on analyses of the American Housing Survey, used either on its own or in conjunction with other data bases, and it has also been based on special surveys done by individual researchers who have designed and fielded their own survey instruments, typically in particular local areas, not nationally.

The last topic I want to address is the major gaps in our knowledge, and the general kinds of strategies we might pursue to close those gaps.

Let me begin with some conceptual issues. In my mind there are at least three different ways in which we might conceptualize housing as it relates to disabled populations or to any population. One conceptualization would see housing attributes—that is, the size of the dwelling unit, whether the dwelling is owned or rented, the characteristics of the neighborhood in which the dwelling is located—as an outcome or a dependent variable that we are trying to explain.

So, for example, we could conceive of a model in which we are trying to determine whether individuals with disabling conditions are more or less likely to be living in physically deteriorated housing and in poor neighborhoods, once we have taken into account other factors that could plausibly explain how the population sorts itself across housing and neighborhood. This relationship could take one of several forms, depending on how we expect the relationship to appear in real life. For example, we might look at what we call main or direct effects of disability status on some housing outcome, such as the quality of the house or the quality of the neighborhood.

Alternatively, we might want to look at both the direct effects and the indirect effects. For example, we might want to see whether the effects of disability on housing quality operated through some other intervening factor, for example, the availability of support services or the continuity of care available to an individual.

A second conceptualization sees these same housing attributes—whether one owns one's home, the quality of the dwelling, its size, and so on—not as outcomes but as inputs or independent variables in a correlational or a causal model in which the outcome or what we are trying to explain—the dependent variable—either has to

do with housing or has nothing to do with housing. What role does housing play in that system?

An example of this conceptualization is a model in which we are interested in the role that living in a physically deteriorated dwelling or neighborhood might play in such outcomes as one's residential stability—for example, how long does one remain living in one's house in the community? Or one's symptomatology or functional status, or episodes of hospitalization, or how long one remains in the hospital or an institution if one does enter such institutions.

Here again we can test this conceptualization in a number of different ways. For example, housing, along with other attributes, might have a main or direct effect on an outcome such as continuity of care.

This is the approach we might take if we wanted to test the notion that housing characteristics facilitated the delivery of services, or monitoring, or follow-up care. Alternatively, it may be that housing interacts with some other factor, for example, continuity of care, to affect a different outcome, such as the quality of one's life. This would be the case if the effects of continuity of care on quality of life depended on some set of housing attributes, for example, whether one lived in stable housing, decent housing, affordable housing.

A third and a final way to conceptualize housing is to see it as both an input and an outcome. This would be the case, for example, if we wanted to examine whether particular features of the housing setting, such as the presence of dwelling modifications, were associated with some other characteristics of housing, such as affordability or whether one rented or owned that home.

Part of my reason for going through these alternatives is to demonstrate to you the range of information that is necessary if we are going to try to untangle the role of housing.

In my reading of the scant literature that is out there, I find that there is often confusion or lack of conceptual clarity regarding which of these alternative relationships the researcher is trying to look at. Some analysts, for example, refer to level of functioning or quality of life as housing outcomes when I think they really mean the extent to which housing affects these two non-housing outcomes. In this case, housing is an independent variable, not a dependent variable.

Turning from conceptual issues, I'd like to address the question: What do we actually know about any of these conceptualizations of housing? Or even more simply and descriptively, what do we know about how the disabled population is distributed across different housing and neighborhood environments?

I noted at the outset that we know very little, but let me emphasize what we do know. I am going to focus my comments on two disability groups that I have worked on most in my own research: individuals who are elderly and individuals who have a severe mental illness. If it is the case that what we know about other disability groups and other age groups is as meager as what we know about the elderly and individuals with serious mental illness, this makes it all the more exciting that we are soon to have at our disposal the new supplement to the American Housing Survey, the Housing Modification Supplement, which Duane will be talking about, because it will cover all age groups and all disability groups.

With regard to simply describing where disabled people live, the only approach that has been available to us to generate estimates of those who are living in special residential settings, such as assisted living, has been to piece together the results of surveys that are done primarily by professional associations, such as the American Seniors Housing Association or the Assisted Living Facilities Association. Because these surveys are understandably sent primarily to the members of these professional organizations, they presumably undercount all of those facilities where the owner or the operator is not a member of the organization.

Unfortunately, we have no way to estimate how many such places are left out nor what the characteristics of these excluded places are. So this is not a very good way to go about estimating size and characteristics. Robyn did mention the new Assisted Living Study that ASPE has sponsored, and in 1997, when that study is out, I think we will learn a lot more about that particular special kind of environment.

What about disabled individuals who are living in private dwellings in the community that are not part of the supportive housing complex? I know that there is a great deal of interest in the audience about this very large group. The only description that I am aware of comes from work that I did using the 1978 National American

Housing Survey, which, like the 1995 survey that Duane is going to describe to you, included a supplement that asks questions about functional impairments.

My analysis focused on one group of disabled adults—those 65 years of age and older—and I found, using these data, that roughly 17 percent of these households were living in housing units and neighborhoods that were very likely to either impede the efficient delivery of services in the home or to preclude their delivery altogether, whether because of the size of the home, the condition of the home, or the condition of the neighborhood.

This work was consistent with earlier work by Marvin Sussman and by Linda Noelker, who each had found, in separate studies based on independent surveys, that housing attributes appear to facilitate a family's willingness to care for an elderly relative. And here we are talking about a very frail older person who is in need of some supportive services.

In later work, we tried to test systematically several different conceptualizations, similar to the ones I noted at the outset, of how housing might affect one particular outcome. The outcome in this work was the risk of institutionalization and again our focus was on frail elderly individuals. In this work we used two data sets: the National Long-Term Care Survey and the National American Housing Survey, and we statistically imputed one data set to the other.

This is a not a good solution to the problem of not having all the variables you want in one data set. This imputation carries with it errors that are associated with the estimates, and certainly it is far better to have one rich data set that gives you all the measures that you need.

In this study, we looked at whether housing attributes had a direct effect on the chances that a frail older person would enter a nursing home, or had an indirect effect by influencing the ability to have either informally or formally provided services to them in the community. We found a small number of both direct and indirect effects of housing that reduced institutional risk.

We also used the combined data set to examine the relationship between the degree of impairment or frailty, on the one hand and the prevalence of housing and neighborhood problems, on the other hand. So, for example, we defined a representative group of elderly using the American Housing Survey and compared that group to a group of very impaired elderly individuals from the Long-Term Care Survey. We defined impairment in terms of three or more ADLs or a cognitive impairment. We found very large differences, with the most impaired elderly having significantly higher rates of physical deficiencies in their dwellings and much higher rates of the absence of housing modifications that would be helpful, given their disabilities.

Some other research that I have looked at has examined the extent to which the frail elderly adapt or modify their housing in order to continue to reside in the community. One paper tried to estimate a behavioral model, looking at the determinants of whether the family would put some modifications into their dwellings.

Several of the analyses suggest that about 10 percent of elderly-headed households have at least one special physical modification in their dwelling unit. But when you look at the research for the frail elderly, the estimates range very widely from about 10 percent to about 33 percent. So I think we have some kind of error or inconsistency in the way people are going about measuring this.

In the one behavioral model that I mentioned, of the likelihood that the elderly household will modify the dwelling, the researchers found that the household's economic status was not a significant factor. This was somewhat surprising , and it led them to the policy conclusion that it would be better to offer targeted services, rather than income supplements, in order to close this particular gap.

It is not clear how much stock we ought to put in this particular finding. The problem here is that the sample was small and idiosyncratic and there were some methodological problems with the analysis. But it is the only one that has actually tried to build a behavioral model.

The National Long-Term Care Survey also includes a single question about whether the frail older person resides "in a building or community intended for older retired or disabled persons." We took a cursory look at this measure in some work we did a few years ago, and we found that, of the elderly who became institutionalized over a two-year period, 60 percent more of them had resided in such a special environment prior to the institutionalization.

The National Long-Term Care Survey has a very truncated set of housing and neighborhood questions, but I remain convinced that we could

learn something from an in-depth analysis of that particular survey. I have been trying to generate support for such work over time, but have been singularly unsuccessful in doing so.

More recently, we have examined the nature and effects of housing and neighborhood on another disability group: persons with serious mental illness. This work was done initially in conjunction with the Robert Wood Johnson Foundation demonstration program on chronic mental illness, and it has been funded by Robert Wood Johnson and the National Institute of Mental Health.

In one analysis we compared the housing and neighborhood circumstances of individuals with serious mental illness with those of the general population living in the same locale. This was a city-level study. We used our own tailor-made surveys to generate measures of housing in neighborhoods for the disabled population, and we used the American Housing Survey Metropolitan Area files to look at the same characteristics for a cross section of the city population.

We found that individuals with serious mental illness generally had considerably higher housing cost burdens than the general population. In addition, their dwellings and their neighborhoods often had higher rates of deficiencies, particularly crime. And these relationships held across income groups, so this is not just an income relationship.

As a purely descriptive piece, which is what I intended with that particular work, it does not establish the relationship between the well-being of seriously mentally ill individuals and the condition of their housing and their neighborhood. This is the fundamental policy question we would like to take a look at.

We tried to address this question in a subsequent study in which we were looking specifically at the feasibility of using Section 8 certificates—the housing subsidy—for the population of individuals with serious mental illness and at the mental health outcomes that were associated with the use of Section 8 certificates.

Understand that what the Section 8 certificate provides is access to decent, safe and sanitary housing, inspected on an annual basis. It also provides access to affordable housing, because at that time the individual paid 30 percent of their income, and the rest was paid by the subsidy.

Our analysis was based on a three-year longitudinal survey that we designed and conducted in two of the demonstration sites that participated in the Robert Wood Johnson program. We found that living in decent, affordable housing and, when necessary, receiving supportive services were associated with dramatic differences in mental health outcomes, in particular with much greater residential stability, reduced length of stay in hospital once an individual was hospitalized, and reduced need for additional services.

So we are very excited about this work because it seems to establish an initial empirical base for housing and mental health policies that acknowledge the contribution of adequate housing in a system of care for persons with mental illness.

Finally, the question: What we need to know? I will try to pull out just a few key topics. First, we need some basic research on the validity and reliability of measuring aspects of the residential environment. I think that the right way to forge ahead in this field is to develop a solid foundation of information about how to measure the things we think we need to measure.

What I have in mind here are rather basic reliability and validity studies that will yield invaluable information about how we ought to word questions, the order of questions, how we ought to construct our indices, which we all do; and it seems to me that we used to pay a lot more attention to these issues in the past than we have in more recent times. I think that is a mistake because we risk producing seriously misleading information in very important policy areas.

Next, we need to develop a profile of the housing and neighborhood circumstances of disabled persons of all age groups, all living arrangements, and all disabilities. This should include the basic physical attributes of the housing settings, whether their housing units contain physical or maintenance deficiencies, unsafe conditions in the home, the social and physical attributes of the neighborhood, whether special modifications are present in the dwelling, and what those are.

To a large extent, we will be able to address this topic in the future, using the new housing modification supplement to the American Housing Survey; though I think we will still be limited in the level of detail we will be able to extract on specific disabilities. And we are not

going to have a very good way of identifying individuals living in special residential settings, though these settings are included in the sampling frame of the American Housing Survey, as long as they are independent dwelling units. How we would go about actually categorizing these different settings is another thorny problem, which was well dealt with in the Maynard and Newcomer paper.

A third question is: How do we look at outcomes associated with different types of dwelling arrangements? Just a few questions here: Do particular housing and neighborhood features facilitate or impede service access or delivery or affect its quality and its cost? Are there particular housing and neighborhood features that are associated with greater or lesser residential stability, risk of hospitalization, institutionalization, and so on? Are there impediments to making adjustments, such as installing modifications in one's home?

I think we can take an initial stab at these questions with the new AHS supplement, though our ability to draw any kind of causal inference will, of course, be very limited because these data are cross sectional in nature. They are not following individuals over time.

To do the job right, we would need to add an ongoing supplement to one of the major national longitudinal surveys, such as the Health Interview Survey, which deals with the full population, or to special population surveys, such as the Long-Term Care or Health and Retirement or AHEAD survey.

A final topic that I think is both important and timely is the determinants and outcomes of moving to a supportive housing setting. We need insights into those factors that have both direct and indirect effects on moves by disabled persons into these environments and the outcomes that are associated with these environments, not only in terms of life expectancy and functional status but also in terms of income.

The preferred approach to studying this topic would be to use an experimental or a quasi-experimental design in which we compared individuals who are in such settings to similar individuals who are not. This is very expensive. In terms of implementation, it would be very difficult to design and to actually carry out such a study. So, again, I would recommend that we add ongoing supplements to longitudinal surveys, such as the HIS, with a block of appropriate questions pertaining to such moves.

How likely it is that any of this agenda will get acted upon is a final question. I am in what I hope are the final stages of negotiations to carry out the work that I have described on the American Housing Survey. It has been very, very difficult to generate what I consider fairly modest support to get this work going, and although certainly the tight budgetary climate in Washington is part of the reason, another part of the problem is that the topic simply is not high enough on anyone's agenda. This suggests to me that we are going to have to garner substantially more support in order to develop the budget that is going to be necessary to add these ongoing supplements to longitudinal studies.

So in addition to having this conference on substantive issues of what we need to know, we might need to get together to strategize how we can generate more support from public- and private-sector funders.

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Duane McGough
Director, Housing and Demographic Analysis Division
Department of Housing and Urban Development

I am responsible for the American Housing Survey on the part of the Department of Housing and Urban Development. We sponsor the AHS, which is conducted by the Bureau of the Census to our needs and specifications.

I want to emphasize one thing very strongly: The American Housing Survey is just what its name implies. It is a housing survey. It is not a population survey or a health survey or a disability survey. It serves many purposes. It is the only current source of good housing inventory information on which we can base our housing policies and implement our programs.

It covers a very wide range of housing issues:

- The structural quality of the house: whether the walls are sound, whether the roof is leaking, and whether there are holes in the floor.
- Suitability of the design for the household, in terms of persons per room, persons per bedroom, or persons per square feet.
- Housing affordability: how all of the many housing costs relate to the income available to the household.
- Home ownership opportunities and barriers.
- Rental subsidy payment needs and standards. We use the AHS to help set fair market rents for the approximately 3,300 housing markets in the country every year, based on bedroom size.

We look at neighborhood quality and amenities. We look at what determines housing values and housing costs. We go on to such things as the relationship of housing locations to employment opportunities, a very important consideration in community development.

The disability supplement, as Sandy mentioned, was added for the 1995 survey. We had one in 1978. It got very little use by researchers. Sandy and maybe a few other people are the only ones, to my knowledge, who have ever used the data. We added it to help determine how people with disabilities are using their housing units, whether the housing units are suitable to their needs, and whether they need additional features or modifications in their housing unit.

I have to contradict Sandy slightly here. We don't cover all kinds of disabilities. We only cover physical limitations in this supplement.

Six broad measures of disability or difficulty with housing-related issues are in this survey, based roughly on housing-related ADLs and IADLs: difficulties in entering or exiting the home; difficulties in five activities related to getting around inside the house; difficulties with five different personal activities; sight problems or hearing problems; need for special modifications, special equipment, or personal assistance.

If anyone in the household has one or more of these problems, those in multi-unit structures are then asked about the presence of six features, such as ramps, handrails, handicapped parking provided with the facility; and if it is not a multi-unit structure, we ask how many floors are in the home. This is to set the stage for the subsequent questions. Those households with at least one household member with a physical limitation are asked if they have any of 14 different structural modifications in the housing unit, if they have personal assistance in helping them deal with their difficulties, if they have one or all of three types of equipment, and if they have any other assistive device.

If they do not have those modifications or equipment, then they are asked whether they need them; that is, whether the house has to be modified to provide assistance for them. They are also asked which of the five physical limitations that I mentioned requires the use of the needed aid.

I have some preliminary results from the 1995 survey. These are crude tallies of sample responses only. They are not weighed. They are not allocated, so the final results may vary slightly, but these will give you some broad indication of the kinds of responses we are getting in the supplement. We'll be making the data available on tape and CD-ROM, possibly late this summer. Publication of the results will be probably 14 months away.

Of all households in the survey responding to the supplement, less than 10 percent reported any kind of difficulty. Less than 3 percent of all households had difficulty entering and exiting. Less than 4 percent of households reported

difficulty going up and down steps inside the house. Only about 1 percent reported difficulty opening and closing doors or going through doors. Less than 2 percent had trouble reaching the bathroom facilities, using the sink, tub, shower, or toilet. Only about 1 and 1/2 percent reported difficulty moving between rooms. This is the same as reaching the kitchen facilities, using the kitchen sink, reaching the cupboards: only 1 and 1/2 percent of the households reported they had those problems.

Cooking and preparing food: about 2 percent. Feeding self: less than 1 percent. Problems with bathing: about 3 percent. Difficulties in grooming and dressing oneself: less than 2 percent. Doing household and laundry tasks: less than 4 percent. Difficulty seeing and difficulty hearing: each less than 3 percent.

Then we asked whether they needed any special modifications, equipment, or personal assistance. I found this very surprising: Less than 4 percent reported that they needed any of those things. As you will see from related responses, I think it should have been higher.

Of all the households that reported one or more of those difficulties, in 88 percent of the cases only one person in the household had that difficulty, and in about 11 percent of the cases, 2 persons had that difficulty. For 3 persons or more, it was 1 percent or less. I think in only 1 case we had a household with 5 people with any of those difficulties.

The responses to the presence of modifications and aids in multi-unit buildings is also interesting. Remember, a multi-unit building is any structure with 2 or more units. It need not have an elevator. It could be garden apartments, for example. Ramps were reported in 16 percent of the cases. Handrails in 65 percent. Automatic doors in only about 1 percent of buildings. Handicapped parking was provided in only 9 percent of the households reporting. Elevators with audio cueing or Braille in 3 percent of buildings, though not all multi-unit buildings have elevators. Accessible public use facilities (lobby, laundry rooms, storage facilities): 6 percent.

For those who reported 1 or more of those problems for 1 or more persons in the household, we asked whether they had certain modifications in their unit, or if they didn't have it, whether they would need those modifications. Ramps going into the house or between floors: less than 8 percent reported the presence of ramps, and of those who did not have ramps, another almost 13 percent reported that they need them but don't have them. Extra handrails or grab bars were the most prevalent: almost 23 percent reported them, and another 25 percent reported that they need them but did not have them. Wider doors and halls for accessibility: less than 8 percent reported having them, and another 7 percent did not have them but said they needed them. Accessible baths: less than 8 percent reported that their baths were accessible, and another 12 percent said that they needed accessible baths. Accessible kitchens: 6 percent in both cases. Special telephones with flashing lights and special hearing aids: about 6 percent had those and not quite 10 percent reported needing them. Elevators or stairlifts in the house: about 4 percent report having them, and not quite 7 percent said they needed them and did not have them.

There are several other modifications we ask about. They all had much, much lower prevalence—2 to 3 percent at most—and of need for them—in the range of less than 2 percent to not quite 5 percent.

Of those less than 10 percent of all households who reported any kind of difficulty, when we asked whether they had or needed personal assistance with ADLs or IADLs, more than 36 percent said they had personal assistance and another almost 40 percent said they needed personal assistance. Using canes, walkers, or crutches: 38 percent used them and another 30 percent said they did not have them but needed them. Using a wheelchair: more than 15 percent used a wheelchair, and another 15 percent did not have a wheelchair but said they required one. Motorized electric cart: less than 2 percent used them, and more than 4 percent who did not have them said that they would need them. Five percent used other devices and less than six percent who did not have any devices at all said they needed some device.

These are raw numbers. It is just a simple tabulation that the Bureau of the Census gave me from that supplement. As Sandy has pointed out, a lot of work still needs to be done with these data; besides cleaning them up and weighting them and finding how many households are involved, they need to be cross-tabulated and analyzed along with all the other variables in the AHS, such as those on income, housing affordability, housing costs, race, age, location,

type of dwelling unit, and a whole number of other items that are available in the survey that can be crossed and compared with these findings.

I personally expected a higher incidence of some of these difficulties. I am not sure how well the supplement works. I think we need to do some more research on how people respond to the survey and how they understand the questions. But I think as a first cut it is a very useful data base, and I hope we can put it on future American Housing Surveys, as well.

The American Housing Survey is a longitudinal survey, but it is longitudinal based on the housing unit. We go back to the same housing unit in the national survey every two years, and in our metropolitan surveys every four years. What we are watching is the flow of households through the housing unit over time, and the changes in the price and quality of the housing unit to see how it changes in the market, and what kind of services is it providing over time. So we can go back another year and find out what happened to the people who were in it, if they left and were replaced by another household or if they are still there, and if they have made more modifications or made other changes in the housing unit.

The American Housing Survey has about 220 questions. Not everybody gets all of them. Some are geared to homeowners, some to renters, some to recent movers; but there is a wide range of variables, and I would encourage all researchers to make the widest possible use of the survey.

Leonard Norry
Assistant Chief for Housing Statistics
Housing and Household Economics Statistics Division
U.S. Bureau of the Census

I have two purposes today: to talk about the classification of living quarters and to describe what the 1990 census can do to show you the housing characteristics of people who have disabilities.

We classify housing basically as housing units or group quarters, which is everything else. A housing unit is living quarters, either occupied or intended for occupancy, that has direct access from the outside and where the people live and eat separately from everyone else in the unit. So you have to be able to live and eat separately and have to be able to get into your unit from the outside, either from a door to the outside or from a common or public hall.

Every other type of living quarters is group quarters. Group quarters have two types: the institutional—either formal care or custody—and the non-institutional. There are many different kinds of each. When we talk about the non-institutional, we talk about group homes and college dormitories or residences where college students live.

We do have a definition in housing that if there are ten or more unrelated people in a living quarters that is not institutional, it is no longer a housing unit. It is group quarters. With fewer than ten, we would call them housing units. Let's say that you had six or seven or eight flight attendants living together. They normally would be occupying a unit that would be thought of as a unit, and that is why we changed it from six or more to ten or more in 1980. We are going to look at that again, because maybe it is too much.

You are also interested in Board and Care, and we at the Census Bureau did a survey for the Department of Health and Human Services on Board and Care places from one of our dress rehearsal sites, central Missouri. A few copies are available from my office.

We have recently tabulated some data on the characteristics of housing units in California, as an example of the kind of data we could produce. We use the census questions on mobility and self-care limitation to get a very rough idea of the number of units in which one or more unrelated people might be receiving some assisted living. The estimates are almost certainly overestimates because the census disability question asks if a person has difficulty with mobility or has difficulty with self-care activities, not whether the person needs help with these activities. For our purposes, unmarried partners are not considered to be unrelated. Persons living alone are not counted.

In 1990, there were 1.1 million persons in California living in households with householders they were unrelated to. Of these, 287,000 lived in households containing three or more unrelated persons, 259,000 lived in households containing two people unrelated to the householder, and 562,000 were the only unrelated person in the household.

In 692,000 housing units, there are either one or two unrelated persons, of which 35,000 contain at least one unrelated person who has a mobility or self-care limitation. Of the 78,000 units with three or more unrelated persons, 6,200 had one or more unrelated persons with a mobility or self care limitation.

There were 645 rooming and boarding houses in California in 1990, and 990 group homes. The average number of people in these categories—40 residents per unit in the rooming and boarding houses and 26 in the group homes—is large, partly due to the rule that if you have 9 or fewer people, it is a housing unit rather than a group quarters.

Of the 26,000 people in each of these two kinds of quarters, 5,500 of the rooming and boarding house residents had a mobility or self care limitation and 8,400 had such a condition in the group homes. That may be a little low.

We've also taken a look at California households according to the disability status of members by the age of the householder. The definition of severe disability here is one or more of the following: under 65 and prevented from working, 15 or over with a mobility limitation, or 15 or over with a self-care limitation.

Of the 10.4 million households in California, 1.5 million contain one or more persons with a severe disability; 1.0 million contain a householder with a severe disability. The

proportion of households containing one or more members with a disability increases with the age of the householder: 33 percent of households in which the householder is over 75 contain at least one member with a disability, compared to 7 percent of households in which the householder is under 35. Households containing a householder between 55 and 64 years of age have members with disabilities 24 percent of the time, higher than the 20 percent rate for those over 65; the higher rate for the younger group is due to the fact that work disability is included for those under 65.

Among households in which one or more persons have a disability, 18 percent contain householders of at least 75 years of age, while only 6 percent of those households with no disability are in that category.

When we compare households by composition (married couples with or without children under 18, other families with or without children under 18, and non-family households), the household type with the greatest number of the disabled is married couples families with no children under 18. The greatest proportion of households with disabilities (26.6 percent) is among other families with no children under 18.

Renter households are more likely to have a householder with a disability than owner-occupied households, 10.6 to 8.5 percent. However, renter- and owner-occupied households are equally likely to have any member with a disability (14.7 and 14.4 percent).

We can also look at housing characteristics. Households with disabled members live in one-family detached houses 54.7 percent of the time, one-family attached 6.2 percent, 2–4 unit buildings 9.1 percent, larger apartment buildings 22.8 percent, and mobile homes 7.1 percent of the time.

We can also tabulate telephone availability and vehicle availability. For example, if you look at households with one or more persons with a severe disability, 80.5 percent have a vehicle available, while households with no persons with a severe disability have a vehicle 92.9 percent of the time.

I think Sandy earlier talked about the cost burden of households with someone with a disability. We collect data on housing costs as a percent of income, so you can get that, too.

The point I am trying to make is that there are a lot of data available. We can cross-tabulate them. We can do it for the United States, for states, for counties, for places, for metropolitan areas, right down to block groups.

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Gerry Hendershot
Deputy for Science, Division of Health Interview Statistics
National Center for Health Statistics

The National Health Interview Survey (NHIS) is a data system operated by the National Center for Health Statistics, which is one of the Centers for Disease Control and Prevention. The NHIS began in 1957 and has operated almost continuously since. NCHS designs the survey, processes the data, and disseminates the results. The data collection is done by the Census Bureau.

In this presentation I will describe the major features of the NHIS as they currently exist: the disability and housing data content of the current basic questionnaire module; the disability and housing data available or soon to be available in recent or current topical questionnaire modules, sometimes called supplements to the NHIS; and the major features of the NHIS redesign and survey integration that will be introduced in the near future.

The NHIS is based on a nationally representative sample of the civilian household population of the United States. Not included in the sample are active-duty military personnel, residents of long-term care facilities, such as nursing homes, and residents of institutions, such as prisons. The sample has about 400 Primary Sampling Units, each unit consisting of a county or a small group of counties. Each state in the current design has at least two Primary Sampling Units.

The current sample has about 41,000 households, in which reside about 100,000 persons. Interviews are completed in about 95 percent of sample households. The high response rate is partly due to the fact that we have excellent interviewers and partly due to the fact that for a large part of the interview we allow proxy respondents, so any adult member of the sample household at home at the time the interviewer arrives can provide the information and complete at least part of the interview.

The HIS is designed as a cross-sectional survey, with a longitudinal option in which, for the most part, sample families were interviewed only once, but at the first interview tracking information and permission for a re-interview contact are obtained. The option to re-interview was used infrequently in the past, but with survey integration about which I will talk later, re-interviews are becoming routine.

The basic questionnaire now in use was introduced in 1982 and has changed very little since. It obtains information on impairments and disabilities in two ways. First, a series of questions is asked about each family member to determine if they are unable to perform or are limited in their performance of an activity that is typical for persons their age. For pre-school children, the activity is play. For school-age children, it is regular school. For working age persons, work or keeping house. And for retirement age persons, independent living, as measured by ADLs and IADLs.

In addition, questions are asked about limitations in performance of other activities. If a person is reported to be limited in their performance of the usual or other activities, questions are asked about the chronic conditions or impairments related to the performance limitation.

The second way in which disability-related information is obtained is by asking if anyone in the family has any chronic conditions or impairments on a list read by the interviewer. If a person is reported to have any of the listed conditions, additional questions are asked about the condition, and all of the information is used later to code the condition to a medical diagnosis.

When we analyze responses to the questions on activity limitation, we find that less than 10 percent of children under 18 are limited in any activity, while more than 40 percent of adults over 65 are limited in activity. We can produce statistics such as these for a wide variety of subgroups and for years 1957 through 1994, the most recent year for which the HIS data are published.

The questions about specific conditions and impairments can be used to study the prevalence of conditions that are of interest. Paralysis of any limb, for example, affects roughly 0.2 percent of children, but more than 1 percent of adults over 65. By contrast, hearing loss is more prevalent, affecting nearly 2 percent of those under 18 and more than 20 percent of seniors over 65.

Again, statistics such as these can be estimated for a variety of population subgroups and for any medical condition in the International Classification of Diseases. But, as a practical matter, the size of the sample is not large enough to allow reliable estimates of many low-prevalence conditions, even when data from several years are combined, which we typically do in this kind of analysis.

Because this is a conference on statistics on housing for persons with disabilities, I would like to be able to tell you now about the wealth of housing information available in the HIS basic module. Unfortunately, the HIS has very little housing information.

There is information on the type of housing the sample family is in, such as house or apartment, mobile home, college dormitory, and so on. There is information on kin relationships among people living together in the same household, that is, whether they live alone, with their children, with their spouse, and so on. And there is other information about the people living together: how many, what their education is, whether others in the family have chronic conditions and impairments and so on. And that is all there is about housing on the current basic questionnaire module.

Although the basic questionnaire doesn't have much housing information, some of the topical modules or supplements to the HIS have more such data. Each year there are several questionnaires on special topics in addition to the basic module, and they are usually in the field for a year, or sometimes two years.

I will describe briefly three such topical questionnaires of possible interest to this audience: the 1990 HIS on assistive devices, the 1994–95 HIS on disability, and the 1995–96 Disability Followback Survey.

The 1990 HIS questionnaire on assistive devices was co-sponsored by NIDRR, and it updated and expanded the scope of information collected in the 1980 HIS on the same topic. It obtained information about the use of all kinds of assistive devices by all members of sample families and about home accessibility features of sample households. For persons using assistive devices, information was obtained about the source of payment for the device.

According to the 1990 HIS, only about 2.9 percent of all Americans—about 7 million people—lived in homes that had some kind of accommodation for persons with disabilities. The most common accessibility feature is handrails, found in about one-half of homes with any accessibility feature, followed by ramps (30 percent), extra wide doors (23 percent), and raised toilets (19 percent). These results are from a short report that was authored by Mitch LaPlante and myself and Abigail Moss of NCHS.

The 1994-95 disability survey was Phase 1 of a two-part survey, Phase 2 being the Disability Followback Survey (DFS), which I will discuss next. Phase 1 was designed to screen for persons with disabilities and obtain basic disability information about them. The survey was undertaken to provide data needed to address major disability policy issues faced by the nation.

The Office of the Assistant Secretary for Planning and Evaluation—Robyn Stone's office in DHSS—took the lead in coordinating the efforts of many federal agencies who needed these data. Ultimately, ASPE and NCHS were joined by 12 other federal agencies and the Robert Wood Johnson foundation in funding and planning the survey.

The Phase 1 questionnaire was in the field for two years, 1994 and 1995, in order to obtain a sample of persons with disabilities that was large enough to do the kind of detailed analyses that were required for policy purposes. For purposes of screening for disability, any indication of disability was counted, including functional deficit, impairments, use of rehabilitation services, receipt of disability benefits, and perceptions of disability. By these rather generous criteria, about 20 percent of the sample, or about 45,000 persons over the two year period, were identified for the Phase 2 Disability Followback Survey.

So, this is two different interviews, two points of data collection in the survey as a whole. The Followback Survey interviews are being conducted 8 months to a year after the Phase 1 interviews. The data are being collected in 8 calendar periods or waves, and Wave 5 is now in the field.

Two questionnaires are being used: one for children and one for adults. In addition to other information about disability, both questionnaires obtain information about housing, including home-accessibility features like those in the 1990 survey; stairs in and into the home; and difficulty experienced in moving about the home. The adult questionnaire has additional information about housing, including questions about a person's

past experience living in Board and Care facilities, assistive living facilities, and so on.

The disability survey, Phase 1 and Phase 2, is one of the largest and most complex surveys ever done as part of the HIS. Its size and complexity have resulted in delays at every stage in the survey process, so the schedule for release of the data is considerably behind the usual schedule for HIS surveys. We now expect to be able to release the 1994 data, the first year of data collection for Phase 1, later this summer. The data will be available both on tape and CD-ROM, and on behalf of the survey's co-sponsors, I am leading an effort to coordinate plans for analysis of the data by federal agencies and their contractors or grantees; and I am being helped with that by Joe Hollowell of CDC and Michele Adler of ASPE. Look at the NCHS Web page for information about the availability of these data.

I will go on to say a few words about some new things that are happening in the HIS, which provide some possible opportunities for adding questions about housing of the kind which have been discussed here already. HIS has been redesigned periodically over its long history, and is currently undergoing another redesign. Unlike earlier redesigns, which attempted to maintain comparability with earlier designs, the current redesign will result in a fundamentally different data system, although some measures will be roughly comparable to those in earlier designs.

The new design will include a basic module that will remain the same each year. That is like the current core questionnaire, and it will consist of three different questionnaires: a short family questionnaire that will obtain some information for all family members, but less than we currently get, and more detailed questionnaires for one randomly selected adult and one randomly selected child.

In addition, there will be at least one periodic module, possibly more, that will be used about once every three to five years and which will remain the same until the next redesign. What that will do will be to go into greater depth on some of the same topics covered by the basic module. Finally, there will be topical modules, like the supplements we have had in the past on special health topics.

The redesigned survey will make use of Computer Assisted Personal Interview (CAPI), which we are told will improve the quality of the data and reduce the length of time between data collection and data release.

The other major change that is going on right now is survey integration. To contain survey costs and to link data from different surveys, the Department of Health and Human Services is linking other major health surveys to the HIS. What that means is that the other surveys will use the HIS sample as their sampling frame. So after the HIS basic module is administered, the other surveys will select from it those people with the characteristics they want and recontact them for another interview. This reduces the cost for the other surveys and allows them to use the data that has already been collected in the HIS.

Two surveys already integrated with the HIS are the National Survey of Family Growth, which has been integrated for two data collection cycles, and the Medical Expenditures Panel Study, conducted by the Agency for Health Care Policy Research; this was formerly was known as NMES (National Medical Expenditure Survey) and before that NMCUES (National Medical Care Utilization and Expenditure Survey). That is now being administered to a sample of people selected from the HIS and is currently in the field. The National Death Index has been linked to the HIS, making it possible to identify persons interviewed in the HIS who have since died, along with the cause of death.

Those are two major new developments—survey integration and redesign of the HIS—which are going to affect the nature of the survey and may provide opportunities for collecting new data on housing.

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Michele Adler: I would just like to echo the theme that there are already a lot of data out there on housing, which have not been tapped as much as they should. In the Survey of Income and Program Participation, starting in 1990, the disability questions are quite detailed, and the SIPP is almost a three-year longitudinal survey. There is information on type of housing, as in the other population-based surveys, but there is also a great deal of information on assets; for example, home ownership, how much is the house worth, and how much is paid for mortgage. And there is a section on mobility that I have never seen analyzed. So this would be a very good survey to analyze, and the public use tapes are out for 1990 and 1991 and, I believe, 1992.

In the Phase 2 disability survey, in addition to the information that Gerry Hendershot mentioned as part of the assets section, in the first interview we have questions on home ownership and value. In the second interview, conducted of people with what we call serious disabilities, there is also information on housing discrimination, and whether people are on waiting lists, and whether people have lived in any of ten different kinds of housing. That is for children and adults.

That data, I understand, will be coming out later this year.

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KEYNOTE SPEAKER

Roberta Achtenberg
Senior Advisor to the Secretary
Department of Housing and Urban Development

As many of you may know, over the period of the last three years, Secretary Cisneros has tried to reshape HUD's view with regard to a whole host of issues, including the very important issue that we address here today, namely, the lack of safe, decent, and affordable housing for low-income persons with disability. I am delighted to be able to speak with you today about that very important issue.

I want to give you some statistics on the housing needs of non-elderly disabled people. We were having a discussion at our table about how difficult it is to come up with good numbers. I am bringing coals to Newcastle here, I guess.

HUD has had extraordinary difficulty in doing just that, but we have made some major strides in the last year, and I want to talk to you about that. When we talk about the numbers as we currently believe them to be, I think they seem insurmountable, and it is particularly difficult to consider these very dramatic numbers when we know that we are in an era of shrinking resources, rather than growing resources, even as the needs of all low-income people are growing.

We in Washington recognize that these are difficult times and growing more difficult. But I am proud to say that even in these difficult times HUD has been trying to reverse a trend of inattention. HUD has been trying to provide persons with disabilities with more housing opportunities, better choices, and expanded options; and much of this is being accomplished through creative redeployment of our resources and through educating HUD employees, contractors, and builders, and trying to change attitudes in the process to become more in synch with the attitudes that are being promoted by the advocacy community. And we try to bring the delivery of the services that we are legally obligated to provide more in synch with the affected communities.

That, of course, is a process, and we always have something to learn. I believe that, under Secretary Cisneros, we have been learning those lessons.

I want to describe the need to you, as it has been described to me by our able researchers. I am not a researcher, so I needed them to describe all of this to me in terms that even I could understand. Now that I believe I have a grasp of these statistics, I am going to try and explain them to you.

Since the early 1980s, HUD has regularly reported on trends in worst-case housing needs, defined as very low income renter households who do not receive federal housing assistance and who have priority housing problems. Priority housing problems include paying more than half of one's income for rent for living in severely substandard housing. Our latest report shows that the number of poor in rental units in the United States with worst-case housing needs reached an all-time high of 5.3 million households in 1993.

And despite substantial efforts of federal housing policy to serve people with disabilities, the incidence of acute housing need remains very high for this vulnerable sector of our population. Earlier worst-case needs reports seriously underestimated the number of poor renter households headed by non-elderly disabled persons.

Our estimates of worst-case needs households rely primarily upon the American Housing Survey, which is a tremendously useful source of information on housing conditions and needs for a representative national sample of U.S. households. However, as discussed earlier in this conference, the American Housing Survey does not systematically assess disabilities among members of the households it surveys. And it is organized around housing units and therefore excludes people who live in institutional arrangements.

Until this year, our best proxy for identifying poor households headed by a non-elderly disabled person was to count non-elderly households with no children who reported receiving SSI or AFDC benefits. We knew that this method resulted in a serious undercount, but we utilized it nonetheless, as the best method that had been developed to date.

This year we developed a new methodology, and HUD's 1996 estimate of poor rental households headed by non-elderly disabled

persons is 4.5 times higher than our previous estimates of persons with disability with worst-case housing needs. For the first time, we obtained access to SSI program audit data, and we were able to obtain more reliable counts on the number of SSI recipients who are non-elderly, disabled adults. And that is what led us to the current estimate, which is now 4.5 times the prior estimates.

These data indicate that 572,000 renter households are non-elderly, disabled, adult SSI recipients living alone. From the SSI audit data we were also able to determine that almost 1.6 million other renter households include a non-elderly disabled SSI recipient. But even this new estimate is a woeful undercount.

There are many reasons that a disabled adult might not receive SSI benefits. For example, disabled workers who qualify for Social Security Disability Insurance and people with temporary disabilities would not be counted through such an estimate. So we know that this is also a woeful undercount. In addition, this count does not include poor households where the adult members are not disabled, but at least one child in the household is.

So there is no question in our minds that, even with the augmented numbers, there are tremendous numbers of worst-case housing needs among persons with disabilities. And therefore the job that HUD has to do is even more dramatic and compelling than it believed it was obligated to do heretofore.

Together these data indicate that the prevalence of priority housing problems is about 38 percent among poor non-elderly disabled adults who live alone and about 44 percent among those living in multi-member households. HUD's current best estimates indicate that at least 900,000 worst-case needs households include a non-elderly adult with a disability. And this is approximately 17 percent of the 5.3 million households with worst-case needs.

Without HUD's rental assistance programs, an even larger number of disabled people would face worst-case housing needs. HUD's rental assistance programs serve almost 570,000 households with non-elderly, disabled, adult members; 344,000 non-elderly disabled adults who live alone receive HUD's rental assistance and another 222,000 receive HUD assistance as part of multi-member households.

Of the non-elderly, disabled adults who receive HUD rental assistance, about one-fourth live in public housing, 37 percent live in privately-owned assisted projects, and 36 percent receive tenant-based assistance.

Today's Forum focuses on data needs and statistics. I know you recognize that behind the numbers are human faces and very dramatic human needs, and I want to tell you a little bit about what HUD is trying to do now to address those very human needs. First, we have been redeploying our resources to create access for people with disabilities wherever possible. We are working closely with our Offices of Multi- and Single-Family Housing to educate them about their role in enforcing, of all things, the Federal Fair Housing Act.

Architects from these programs regularly review blueprints and construction to determine eligibility for HUD mortgage and insurance. From this point forward, these architects are also being instructed to review new constructions for compliance with the Federal Fair Housing Act. In other words, we are telling builders that HUD money won't go to construction that isn't accessible to people with disabilities.

You might have thought that this was already being done. You are looking at me with eyes of astonishment. But I can tell you that only at the insistence of some of the advocates sitting in this very room, and when we brought on board somebody who truly understood and appreciated what this could mean, did we begin traveling down the right path. Quite frankly, this has happened as a result of hearing what the affected community is saying, opening our ears to the legitimate concerns and complaints of the advocacy community, developing numbers that are relatively sound numbers compared to the numbers that existed heretofore, and recognizing that HUD had a leadership obligation in this area and one that this secretary was willing to have HUD assume.

It also required admitting that "mistakes were made," as we say in Washington: "I didn't make any mistakes, but mistakes were made." Now we are trying, slowly but surely, to address those mistakes, and to correct our own internal omissions is one of the mistakes that needed to be addressed. Under Secretary Cisneros we are addressing it.

For construction to which the Federal Fair Housing Act doesn't apply, HUD has been promoting a concept called "visitability."

Actually, this concept was first developed by a group of advocates with disabilities. They wondered why new construction is still being designed and approved by HUD with barriers for the disabled. Why do we need three steps in front of a front door? Why can't doors be a few inches wider so that a person in a wheelchair can pass through those doors? They were asking us those questions.

We decided to open our ears and to recognize that these questions that they were asking us were actually good questions, and we in turn began asking questions ourselves. The answer is that in most cases there is no reason in the world why barrier-free construction can't take place. And, through directives that the secretary has issued in the last few weeks, we are beginning to encourage barrier-free construction so that visitability might be the order of the day.

We are asking that HUD-funded construction have at least two easy, low-cost features, with no-grade entrances wherever feasible and wide interior doors that can accommodate a wheelchair. Typically, in most construction situations, these are either low-cost or no-cost approaches to take, and there is no reason in the world why HUD can't insist on these kinds of construction formats wherever feasible.

We have come to see, because of the dramatic numbers that we talked about before, that HUD has to be much more active and much more aggressive when it comes to making sure that the modest resources that the Congress had put at our disposal are much more effectively utilized. And we intend to do just that. We want to open doors and keep them open and make sure that they are wide enough for all to enter.

We are committed to ending discrimination wherever we find it, and that includes the very woeful cases of discrimination against persons with disabilities, cases too numerous to do anything other than plague the conscience of this nation.

Some of the progress that we have been making has been slow. Much of it has been painful, and we have been forging ahead. It is my fervent hope and I know that it is a national need that we have a little more time to accomplish this important task, and I hope you will get us there.

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WORKING GROUP:

DISABILITY HOUSING STATISTICS

Facilitators: Bob Newcomer and Bob Maynard, University of California—San Francisco

The discussion began with the topic of disability definition. It was pointed out that definitions for some surveys, such as those for the Social Security Administration, were strongly influenced by program eligibility criteria. The ability to change definitions is limited by needs of the particular survey's client.

It was suggested that a consistent set of stem questions across the different surveys should be created. This would be focused on functional limitations (ADL, etc.) rather than trying to derive a standard definition.

The question of defining institutional versus non-institutional housing was raised. It was noted that the definitions are increasingly fluid and that, because of de-institutionalization, the clear desire of most individuals with disabilities to live in a community setting, and the development of more home-based services, many of the old categories are irrelevant.

There is a need to be able to discern emerging trends in disability housing. This would make the information more valuable for users such as housing developers.

Instead of looking at housing type, one person argued that we should be more interested in determining where disabled persons are residing, and then focus on defining housing types. Another participant felt that we still needed a consistent and precise "taxonomy "of housing type. It was also proposed that housing needs, rather than existing housing patterns and stock, should be assessed.

The problem of differing state licensing definitions for housing was raised. Some states (such as Texas) have minimal or no regulation of group housing, such as Board and Care facilities. States that do regulate group housing vary greatly in what they consider to be group housing. States also vary greatly in the quality and type of data that they collect. This complicates the process of developing a national sample.

The difficulty of implementing housing surveys in the field was discussed. Even when fairly clear definitions are available, the surveyor has to make many decisions about which category a given building or unit falls into. It is often not clear:

- whether a building is a group quarters,
- what category of group quarters it falls into,
- whether services are being provided.

A participant stated that the Decennial Census is very difficult to change, that funding is likely to be a continuing issue, and that we should focus instead on smaller scale special studies. Another participant responded that the Census tracts and definitions were the base for a number of the other surveys, and that it was therefore important to assure that census definitions and questions were appropriate.

There is a need for longitudinal data in order to ascertain trends in housing and service patterns.

The American Housing Survey and the National Health Interview Survey were specifically discussed as vehicles for providing better data. It was noted that severe disability is "rare," and that both oversampling and increased sample sizes would be necessary. This brought back the issue of cost and funding for carrying out changes. The consensus seemed to be that the HIS, which has had an extensive disability supplement, offered the best existing vehicle for provision of disability housing data. It would require a housing supplement and an expanded sample frame.

The participants felt that, in order to improve the data, a demand must be created through activism. This can come in three areas:

- in the legal arena, to meet the requirements of ADA and other legislation;
- from groups that have an interest in accommodations;
- in the economic arena, from builders, the construction industry, lenders, etc.

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WORKING GROUP:

POLICY NEEDS FOR HOUSING DATA

Facilitator: Thea Spires, Maine Department of Mental Health and Mental Retardation

The goal of this session was to define and inventory the types of information and data that are needed for housing policy. Given that, the group in attendance covered a broad spectrum of topics, both methodological and substantive, which participants believed would greatly improve the reliability, applicability and usefulness of statistical research on housing issues. Session participants focused more upon best case scenario issues and concerns, rather than discussing the feasibility and practicality of their recommendations.

Initial discussion focused upon the limitations of current survey methodology in adequately including all persons with disabling conditions. The major liability of gathering housing data from nationwide surveys, such as the NHIS, was seen to be one of sampling design, in which the basic unit of analysis is that of households as opposed to people. Participants felt that these surveys exclude large numbers of people with disabilities residing in institutional settings, or within group and congregate living arrangements that are not sampled in current methodological designs. Social Security data is likewise inadequate, in that its sampling frame is restricted to Social Security beneficiaries.

Much discussion centered upon the limitations of current paradigms, models, and levels of abstraction in survey research, both to ask the appropriate questions and to come up with findings that present the actual desires, needs, and concerns of people with disabilities. The recognition of people with disabilities as being socio-culturally, economically, and functionally diverse is lacking in current research. Methodology rooted in a medical model leads to examining issues only in terms of basic need and its relation to physical functioning.

Participants proposed a research agenda encompassing a broad definition of disability, not only including functionality within current medical diagnostic classifications, but assessing the diversity of experiences and interpretations of disability across types of impairments, geographical locales, and cultural and economic backgrounds. To accomplish this, training on how to survey people with various disabilities (e.g., mental retardation) and from differing cultural backgrounds (e.g., recent Asian immigrants) needs to be developed and training programs implemented.

Participants suggested several methods that could potentially be employed to improve the overall reliability of current survey research efforts: Of great benefit would be the further disaggregation of available data by race, income, ethnicity, geographical location (accounting for variation at both state and local levels), family size (accounting for non-traditionally-defined family structures), and type of current housing. There is also a need to gather the same level of housing information on people with disabilities as for all other Americans, including type, ownership, location, number in household, etc. Finally, data could be further disaggregated by functional characteristics, rather than by condition categorization.

A lengthy discussion took place concerning the need to reevaluate the current criteria used in evaluation research. The determination of what constitutes effectiveness needs to be recast in terms of what people with disability want and need, as well as what they find optimum and acceptable. To achieve this, measures of consumer satisfaction, quality of life, consumer choice, and preference as to where and how to live need be incorporated into housing data. Basic market research is needed on people with disabilities, who should be viewed as viable consumers within the housing market.

Policy development could benefit from knowing why people with disabilities live where they do. Data should be gathered from people with and without disabilities, the disparities between them should be examined across a wide range of variables. Proposed questions included:

- What are the housing arrangements of

people with disabilities as compared to those of everyone else in a given locality?
- What is their accessibility to housing in areas where other people in a community live?
- How pervasive is the fear, stigma, and discrimination against people with disabilities in a given community, and to what extent does this foster segregated living arrangements?
- What are the attitudes and feelings of people in a community where there has been effective integration of people with disabilities? What are the factors and practices in these communities that have fostered successful integration?

Finally, recommendations for the collection of housing data to benefit the current policy agenda of people with disabilities are as follows:

- Data on effective housing to guide states dealing with block granted housing programs (e.g. cost, location).
- Data on the costs/benefits of good and effective housing (e.g., realized savings in hospital and medical services utilization costs, overall costs in building adaptation/modification that fosters living in previously restricted settings, and cost savings from a lessened need for people with disabilities to move from one setting to another).
- Under current federal programs, what are the unmet physical and cognitive needs of people with disabilities?
- Data on reasonable accommodation for people with psychological disabilities in terms of the structural needs for increased accessibility.

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APPENDIX

An Assessment of National Statistics on Supportive or Assisted Living for Those With Disability

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Almost 8 million Americans need assistance from another person to accomplish everyday tasks. Three million of this population are not receiving this assistance on a regular basis.[1] Among the means of assuring access to appropriate assistance is through one's living arrangement. Most individuals with limitations in their ability to live without assistance elect, either from preference or necessity, to live with family members or unrelated individuals in single family housing units or apartments. This presumably assures assistance in such basic activities as shopping, housekeeping, meal preparation, and transportation. Additionally, it is common that personal care assistance, such as in bathing, dressing, toileting, and eating may be available through these means. To the extent the living situation depicted here occurs among five or more unrelated persons, it is usually treated differently by local zoning rules, fire and safety ordinances, and state regulations than if the individuals were related (or if there were fewer than five unrelated individuals living together). Units with five or more persons are typically defined as a form of group housing. The level of services provided by the housing facility or operator may also determine whether this living arrangement needs to be licensed as a form of special care facility. As discussed below, states vary substantially in the criteria used to determine whether a facility needs to be licensed.

The somewhat arbitrary decision rules that differentiate independent living from group housing have had major implications for how the U.S. Census is conducted. These same rules affect the sample design and generalizability of many other surveys of the aged and disabled populations. The net result is that both national and community-level information about the housing and living arrangements of persons with disabilities may be substantially biased—particularly among persons living in the so-called group quarters.

This report examines the major national population and housing surveys to identify their strengths and limitations in reporting the supportive or assistive living arrangements of persons with disabilities. Specific attention is given to sample construction and the interview items or measures used. Modifications in design or measures are suggested for enhancing the appropriateness of each survey. Appropriateness in this context includes both how supportive housing or assistive living arrangements are defined and how disability is measured.

These are timely public policy issues. One salient factor is the number of persons affected by disabilities living in supportive group housing. The Select Committee on Aging of the U.S. House of Representatives[2] estimates that approximately one million elderly and disabled persons reside in more than 68,000 licensed and unlicensed residential facilities. These estimates do not include persons living in family units or with fewer than five nonrelatives. Very little is currently known about this population or their housing units, especially those in unlicensed facilities.

A second factor is an emerging policy within many states that allows licensed residential facilities to serve individuals with disability levels that formerly would have required transfer into nursing homes. A related factor is the apparent preference of the disabled population to avoid institutions while maximizing individual choice in the selection of housing for themselves. For the non-aged disabled especially, this may often include the choice of unlicensed housing, either in individual apartments or in small group settings.

Policy decisions are affected by the lack of adequate data on current housing and services provision for this population. Without such data, it is difficult to isolate problems, identify trends, and forecast or evaluate the results of policy changes. Supportive housing for the aged population has been studied more than housing for younger disabled groups, but there are substantial limitations in knowledge for both groups. Aggravating the data problems is a multiplicity of names and forms of supportive living arrangements, different licensing laws across states, lack of accurate statistics on the number of disabled residing in

[1]Litvak, S. Presentation to the National Council on Independent Living, 1990, from the World Institute on Disability.

[2]U.S. House of Representatives, Select Committee on Aging, "Board and Care Homes in America: A Nation of Tragedy" a Report by the Chairman of the Subcommittee on Health and Long-Term Care. House of Representatives 1989, pub. no. 101-711

such housing, and a paucity of data on demand for services.

Defining Group Housing

Group housing is a term used to encompass many types of living situations. Among them are institutions, such as nursing homes and mental health hospitals, and noninstitutions, such as rooming homes, communes, residential care facilities, homes for the aged and disabled, and halfway housing. For our present purposes we are particularly interested in the situation in which an adult individual is receiving food and shelter from a nonrelative.[3] Licensed facilities (such as residential care facilities or RCFs) are presumed to be differentiated from unlicensed facilities (i.e., "board and care" homes as distinct from boarding homes) by the degree of protective oversight and personal care available. Both RCFs and boarding home services usually include cleaning the resident's room, laundering linens, and the provision of meals. Licensed facilities are usually responsible for helping with transportation and shopping; supervising residents' medication; assisting in obtaining medical and social services; and on a more limited basis assisting with dressing, grooming, eating, bathing, and transferring. Some licensed facilities can provide assistance for those with special needs, such as those using oxygen and assistive devices, or with cognitive impairments.

State governments, in statutes and regulations, differentiate the levels of care that can be provided in licensed facilities such as RCFs as opposed to nursing homes. Distinctions are also made in the allowable levels of care among varying designations of licensed housing.[4] For example, it has been common to prohibit RCFs from administering (as distinct from supervising the taking of) medications or housing residents who receive regular nursing care (such as from a home health agency). Another common restriction is that residents be able to exit the building on their own during a fire or other emergency.

Both licensed and unlicensed facilities vary in their architectural design. This further complicates how such units are classified for many survey samples and how the data are compiled. Facilities may offer independent apartment units, with shared or common services available on site. Alternatively, they may offer only single or shared bedrooms, with full access to kitchens, bathrooms, and other features common to any home. The former case may be defined as independent living or as an institution, depending on the licensing status, but it would likely not be defined as group housing. The latter situation would almost invariably be defined as group housing, if there were five or more unrelated individuals present. Identical facilities with fewer than five residents would be defined as independent housing (unless the facility were considered an institution).

These definitional complexities have reduced the effectiveness of all the major U.S. surveys of health status and housing, resulting in less than perfect information about the living situation of persons with disabilities.

Methods

Over 75 survey instruments were evaluated and an extensive literature review was conducted to identify potentially relevant data sources. These materials were supplemented with discussions with agency personnel involved with the major data sources to further clarify the survey methodologies. Limitations in sample size, sample frame,

[3]A variety of terms are used by states and others to label licensed residential care. Most common in regulation and statute is board and care, and residential care. Other labels include adult congregate living, adult foster care, community care, assisted living, domiciliary care, personal care, sheltered care, supervised care. Terms like boarding homes, congregate care and group homes usually refer to unlicensed facilities. Continuing Care Retirement Communities (CCRCs) and homes for the aged often have a combination of independent living units, personal care or RCF level care, and nursing units all on the same site. The RCF level (and in some states the independent living units) are usually licensed. "Assisted living" has emerged as a popular label for supportive or personal care housing.

[4]Facilities are classified by the level of care, size and population served. Among the states, at least seven groups are served: the elderly, mentally ill, developmentally disabled, mentally retarded, alcohol and/or drug abusers, physically disabled, and children. Commonly, a facility may be licensed for more than one population (e.g., elderly and physically disabled, MR/DD).

infrequency of collection, and inadequate measurement of living arrangements or disability status precluded most of the surveys from extensive consideration. Appendix 1–A provides a synopsis of the principle data sets reviewed. Appendix 1–B is a synopsis of the subset of surveys which received in-depth evaluation. Five of these are reviewed more fully in the following section. In combination, these surveys offer excellent options for the measurement of disability, sample designs for identifying alternative living arrangements, approaches for monitoring housing choices, and measures of housing type and living arrangements.

Findings

No single current survey is fully adequate in providing data on the living arrangements of those with disabilities, but with minimum modification at least two could be much more effective. Five factors contribute to the current inadequacies:

- Surveys that provide extensive housing data have little or no information on disability, health status, and the services available within the housing.
- Surveys that have extensive health and disability data provide little or no housing or living arrangement data.
- Surveys either attempt to exclude institutions and some forms of group housing to limit their sample frame to the noninstitutionalized population or they rely on proportionate weighting of the population in "group settings."
- Both these sample frame designs produce either an underenumeration of the disabled population, or a sample of specialized living situations that may be too small for detailed subgroup analysis.
- The definitions used for the enumeration and selection of eligible housing units are problematic, leading to likely problems in inappropriate sample exclusions.

The five surveys summarized in the next section provide further documentation for these findings. The National Health Interview Survey excels in its definition of health and disability status, but it has an inadequate sample frame for the disabled population and lacks an adequate categorization of specialized housing and services. The Disability Supplement addresses these issues to some extent, but there continue to be problems in the basic sample frame. The Decennial Census has substantial problems in the terms and procedures used to classify housing types, and it collects minimal information on health or disability status. The American Housing Survey , also done by the U.S. Bureau of the Census, presents by far the best definition of housing type and characteristics, but has limited health and disability characteristics. The Social Security Administration New Beneficiary Survey has a reasonable size and reasonable health and disability definitions, but it suffers from sample frame and housing categorization limitations. The Medicare Current Beneficiary Survey has health, disability, and some housing and services data, but it is limited to Medicare recipients and therefore excludes a significant portion of the disabled population. The housing categorization suffers from the definitional inadequacies of the other surveys, but the population is selected independently of their setting, permitting this survey to have independent living, group housing, and institutions all represented.

Recommendations

Modifying major national surveys is not a trivial undertaking, since it involves the coordination of sample frame development efforts among many agencies. It can affect trend lines and forecasting It can have substantial cost implications, arising from new questions or expanded sample sizes. Further affecting any changes is the politics of negotiating new or replacement questions. Our recommendations have been made recognizing these constraints.

Recommendation 1

Organize and convene a Policy Forum to discuss the findings and conclusions of this report.

The purposes of the forum would be to

- Discuss how to modify sample frame rules used to classify institutional and

noninstitutional group housing and specialized living arrangements for the disabled and aged in the U.S. Census, the National Health Interview Survey, the American Housing Survey, and the Medicare Current Beneficiary Survey.

- Discuss possible measures for classifying special supportive living arrangements within the American Housing Survey and the Medicare Current Beneficiary Survey, and describing the services provided or available to residents.
- Discuss possible measures for health, and disability status items that could be incorporated into the American Housing Survey.
- Discuss the feasibility of organizing survey tabulations or files so that living arrangements of the disabled can be more fully and explicitly analyzed. For example, given the trend in the disabled community toward less restrictive living arrangements (that is, away from institutional settings and toward informal models such as shared housing or independent living), it seems appropriate that sample frame rules (and data tabulations) should include any housing situation in which two or more disabled individuals, or a single disabled person and an unrelated caregiver, are housed, irrespective of services offered or legal structure pertaining to the facility's licensing status.
- Suggested participants would include the Interagency Subcommittee on Disability Statistics, the Bureau of the Census, the National Center for Health Statistics, and the Health Care Financing Administration.

Recommendation 2

Develop and test measures for household and living arrangement classifications that could be incorporated into the sample frame enumeration used in the Census and other surveys, as well as for classifying the housing types used in the surveys.

Recommendation 3

Initiate discussions with state and community officials to identify means for enumerating licensed and unlicensed supportive housing arrangements for incorporation into the sample frames used above, and for inclusion into the Area Resources File.

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MAJOR SURVEY SUMMARIES

American Housing Survey

The American Housing Survey (AHS) is conducted by the American Housing Survey Branch of the Bureau of the Census. It is conducted every other year. In 1995, the sample consisted of approximately 61,000 units. The sample areas, called Primary Sampling Units (PSUs) are stratified by region and urban/rural locations. Both national estimates and estimates of selected metropolitan areas are available. Census Enumeration Districts are sampled from within the PSUs. Housing units form the sampling unit. An important feature of these surveys is that generally the same housing units remain in the sample year after year, and it is the housing unit rather than its occupants that is followed.

Strengths

This data set has extensive information on housing stock, including type of housing, living arrangements, and quality of housing. Its housing typology is particularly useful. Its coding includes categories for "non-institutional, special places." Sub-categories are quite detailed and have extensive descriptions. Types that may be relevant to analysis of supportive housing for the disabled include Boarding House (code 76); Combination Boarding and Rooming House (code 76); Commune (code 92); Non-transient Hotel or Motel (code 71); and Independent Group Residences for senior citizens, the handicapped, and functionally disabled (code 94).

The AHS has further advantages in its nationwide coverage, stratified, random sampling, frequency of application, consistency with census tracts (from which sampling is done), and detailed definition of household membership. Further, information on households with SSI and disability income programs is collected in detailed categories. In addition to housing data, the AHS currently solicits a significant amount of demographic, financial and geographic data, including education, marital status, cost of housing, and transportation use. A third possible strength of the AHS is that the sample (approximately 61,000 units) is large enough to identify a statistically significant sample of non-aged disabled residents, but it may require an oversampling of special units to permit a generalization to this subset of housing types.

In 1995, for the first time, the AHS included a brief "Housing Modification Survey." This addition included a self-report on Activities of Daily Living, vision and hearing status, and mobility for household residents. It also asks about home modifications that have been made for disability. The future periodicity of this supplement in unclear.

Finally, the AHS has strong support from industry users, such as the National Association of Realtors, who may have an interest in improved disability housing data.

Weaknesses

The most important limitation of the AHS instrument is that it has a limited amount of data on the disability status of residents. A second problem stems from their definition of "non-institutional special places" and a definition of group housing based on the criterion of five or more unrelated persons living together. The special places classification includes potentially relevant categories of housing, such as "rooming house," "commune," "rest home," and residential care, but the delineation and differentiation of housing units into these various classes is affected by interviewer interpretation of a particular facility's fit with the operant definition, and state variation around the classification of facilities. The absence of an individual housing unit within one of these special places would render the housing unit ineligible for the survey, thus affording no information on the inhabitants. There is not comparable survey information on these ineligible special places. This decision rule applies only to facilities of greater than five beds.

Possible Adaptations

- Improve the health and disability status section of the AHS interview.

- Add a section to the instrument to obtain information on supportive services in special units.
- The definitional and data collection techniques of the AHS and the Decennial Census need to be refined and coordinated.
- Develop a subsample of specialized housing units to permit the national profiling of trends in these settings.

National Health Interview Survey and Disability Supplement

The National Health Interview Survey (NHIS) is a continuous national survey sponsored by the National Center for Health Statistics. It provides data on acute conditions, limitations of activities, injuries, disability days, physician and dental visits, and selected chronic conditions. It also provides standard demographic information and modest housing data.

NHIS uses a probability sample of civilian non-institutionalized households. Sampling is done by the Bureau of the Census; it consists of approximately 50,000 households representing 130,000 individuals. The sample is stratified to reflect regions and metropolitan areas. There are 210 Primary Sampling Units (PSUs), from which Census Enumeration Districts are selected. Small land areas or groups of addresses are assigned for interview. Data is collected on all household members within this area probability sample of housing units. Some sample units are located in places with special living arrangements, such as dormitories, institutions, convents, or mobile home parks. These types of living quarters are specified as special places. Units defined as institutions are excluded from the sample.

Most NHIS survey waves include supplemental surveys for special groups identified during the primary survey. In 1994–95, a supplemental survey on disability was conducted to obtain additional information on the living arrangements and caregiver resources of this population. The survey instrument for the supplement includes questions on ADLs and IADLs, mental retardation and developmental disabilities, physical, emotional and cognitive impairments, transportation, employment barriers, home access and accommodation, and services utilization.

Strengths

The NHIS in general and the Disability Supplement in particular, offer excellent data on health and disability status and many related areas. Because of the main survey's continuous sampling, it is useful for the cross sectional monitoring of changes in condition prevalence for a wide range of conditions and among various ethnic and economic subgroups. The large sample size used in this survey assures a minimal standard error for prevalence estimates for major conditions and subpopulations.

Weaknesses

Although the basic instruments have some questions on housing type, the categories do not capture the variations in supportive living arrangements or in specialized housing. Like the American Housing Survey, there is variation among enumerators in the inclusion of licensed supportive housing units. This occurs, in part, because of differences in state licensing requirements and by the discretion afforded the enumerators in defining eligible and ineligible housing units. In 1994, more than 1,000 surveyed units (corresponding to a population estimate of more than 4 million people) were classified as "unkown." The instrument used for the Disability Supplement provides extensive information on support services for those with impairments, but the standard instrument does not. Even in the special instrument, many of the quality of care items apply to the age 70+ population only.

Possible Adaptations

- Implement a regular schedule for a fielding of the disability supplement.
- Add a more complete housing component, perhaps using the AHS format for categorizing special places housing within the disability supplement.
- Extend the quality of care questions to all ages among the disability group.

Decennial Census of Population and Housing

The Decennial Census encompasses the entire U.S. population. It provides data cumulated at the census tract level on household demographics (e.g., age, education level, race, ethnicity, sex, marital status, migration, mobility), income, income source, labor force participation, occupation, and type of dwelling, (e.g., home or apartment, mobile home, trailer, house, apartment, and qualified group housing). The number and relationships of persons in each household is also compiled. Included among the many tabulations and tape files is a summary statistics file representing a 100 percent count of persons in "group" quarters. Group quarters include persons in institutions and noninstitutions.

Strengths

The major value of the Decennial Census for the present purposes is its 100 percent enumeration of the civilian population. This yields a basis for community level analyses and trends monitoring, and the application of synthetic estimates of condition prevalence, and service use.

Weaknesses

The living arrangement categories, especially for specialized housing, preclude extensive application of census data for those in special living circumstances. For example, the Decennial Census uses two major housing categories: regular housing units and Group Quarters. The Group Quarters category is further divided into institutional and non-institutional components. Institutional Group Quarters includes "skilled nursing facilities," "homes for the aging," "ICF/MR" facilities, "halfway houses/correctional," "long term care rooms," and "residential treatment centers," among others. These can be of any size. Non-institutional Group Quarters include "rooming/boarding homes," "MR," "mentally ill group homes," and "non-transient hotel/motel," and must have *ten or more unrelated residents*. Non-institutional Group Facilities with less than ten unrelated individuals are categorized as Regular Housing Units. This leads to a significant under-counting of supportive housing facilities, many of which, especially of the unlicensed variety, are known to be small in size.

Further complicating this issue, the methodology for identifying facilities into group housing is less than rigorous. A facility with nine unrelated residents may be listed by one enumerator as a "home for the aged," but it can also be considered a boarding home with fewer than ten persons, and thus put in regular housing units by another. Similarly, an apartment in a supportive housing complex is considered as independent housing, but residents with private or shared rooms in similar facilities would likely be defined as in group housing. Some of this confusion could be reduced if the services provided or available in Group Quarters were specified.

Another limitation of the Census is that it collects minimal significant direct information on health, disability, or functional status.

Possible Adaptations

- The most practical change would be to clarify the enumeration process for the multitude of specialized living arrangements, and to create data files and tabulations that are specific to these settings.
- The housing or living arrangement categories used here should be consistent with those in the American Housing Survey. The Bureau of the Census conducts the AHS, the HIS, and the Decennial and Current Population Surveys, reducing the barrier to the creation of common definitions and cross-identification.
- Consideration should also be given to adding questions applicable to specialized living settings that describe a facility's physical and staff characteristics, as well as the services provided.

Medicare Current Beneficiary Survey

The Medicare Current Beneficiary Survey (MCBS) is sponsored by the Health Care Financing Administration as an ongoing, multipurpose survey conducted among a probability sample of Medicare beneficiaries. Also collected are data on health conditions, functional status, health care utilization and

demographics, including income and vital statistics. To date, there has been only one survey round in which there was a supplementary interview conducted with a particular set of survey recipients, in this case for those receiving home health care.

The sample is derived from 107 Primary Sampling Units (PSUs) consisting of metropolitan areas and clusters of non-metropolitan counties. Separate strata are compiled for the disabled under the age of 65 and for five cohorts over the age of 65. The strata are of equal size, producing a total baseline sample of 12,000 persons. All cases receive an initial interview and a reinterview every 4 months, through a total of 12 interviews over 36 months of tracking. The original panel was first interviewed in 1991. Since 1994, there has been a phased supplemental panel of new beneficiaries. Phasing is designed to replace one-third of the panel annually, thus assuring maintenance of a longitudinal panel and an ample sample for cross-sectional analysis.

Strengths

The MCBS provides longitudinal data on multiple age cohorts. Being focused on health care utilization, it provides extensive data on health and disability status, as well as some types of service utilization. Unlike most other national surveys, the MCBS includes both community and institutional populations. These are selected proportionate to their distribution among all eligible beneficiaries. Living arrangement data are collected for both those in the community and those living in institutions.

Weaknesses

A primary limitation for purposes of supportive living arrangement monitoring is that the housing categories used in the survey do not fully delineate the range of alternative facilities, both licensed and unlicensed, that characterize specialized living arrangements. Sample size, particularly of the non-aged disabled, is not large enough to capture a sizable number of specialized living arrangements using the current proportionate weighting methods. This limits the ability to analyze living arrangements by housing subtypes. Also, since this survey covers only Medicare beneficiaries it excludes the disabled population that has not qualified for this program.

Possible Adaptations

- The addition of a more delineated housing classification would enhance the utility of MCBS for tracking supportive housing arrangements.
- Similarly, the ability to organize living arrangement information by the health and functional status of household members would be useful in differentiating licensed from unlicensed supportive housing arrangements.
- Periodic supplemental surveys of specialized housing should be considered as a means of expanding knowledge of the population living in such settings.
- Given the primary intent of the MCBS in dealing with its service population, the problem of excluded disabled populations does not seem easily rectifiable.

Social Security New Beneficiary Survey

This survey provides longitudinal data on new SSDI beneficiaries. It is sponsored by the Social Security Administration. Personal interviews with a random sample of non-institutionalized beneficiaries and their spouses are conducted. The size of the sample in the first wave was 13,962, including 12,128 original sample persons and 1,834 widows/widowers of original sample persons. The first wave was collected in 1982 by SMSA. The second wave was conducted in 1992, and was collected nationally. Data collected include demographics, employment and income, health conditions that limit ability to do work, and limitations of activities (ADL/IADL). There are also data on long term care services in residential facilities.

The Social Security Administration conducts a number of other surveys on its recipients, such as the Continuous Disability History and the Supplemental Security Income Stewardship Survey. These all may have some utility in studying the supportive housing needs of the disabled but have sample design or measurement flaws that are similar to those of the New Beneficiary Survey.

Strengths

This survey is focused strictly on the disabled population. It provides a relatively large sample size of almost 13,000 individuals. The survey provides excellent detail on disability limitations and health status.

Weakness

Like the other major surveys described earlier, the New Beneficiary Survey does not adequately distinguish among the alternative specialized living arrangements and service categories. Because it surveys only qualified beneficiaries, it excludes all the disabled who have not qualified for benefits under Title 11. Finally, the survey is designed to track the experience of individuals when they first come into benefit. Consequently, this survey does not necessarily reflect the situation of the full disabled population.

Possible Adaptations

- The housing, living arrangements, and services section of the instrument should be brought into alignment with whatever changes are made in the Medicare Current Beneficiary Survey.
- As with the Medicare Current Beneficiary Survey, the Social Security Beneficiary Survey is directed only at a specific service population. Therefore addressing the problem of excluded individuals cannot be easily addressed, nor are we recommending that this issue be addressed.

Appendix 1–A: Data Sets from the National Center for Health Statistics and Other Useful Data Sets

National Center for Health Statistics Data Sets

Data Set (Acronym)	Sample	Geographic Area	Periodicity
Access to Care Survey (ACS)	National follow-up survey drawn from respondents to NHIS. Survey will characterize the experience of obtaining medical care and provide detailed information on the nature of access problems. (Survey)	Region	1994-first data collection; 1995-data will be available; completed once.
Hispanic Health and Nutrition Examination Survey (HHANES)	Cross-sectional study of noninstitutionalized, selected Hispanic subgroups between the ages of 6 months and 74 years. Data includes prevalence of selected diseases, substance use, body weight and other health indicators. (Survey)	County/ Burroughs	1982-84-data collection; study completed once.
National Health and Nutrition Examination Survey I (NHANES I)	Probability sample of 32,000 U.S. civilian non-institutionalized population, ages 1-74. Established baseline data for NHANES I Epidemiologic Follow-Up Study. (Survey)	Region	1971-75- data collection; study completed once.
National Health and Nutrition Examination Survey II (NHANES II)	Nationwide probability sample of 27,801 civilian non-institutionalized U.S. population from 6 months to 74 yrs. (Survey)	Region	1976-80-data collection; study completed once.
National Health and Nutrition Examination Survey III (NHANES III)	Random sample of personally interviewed persons living in households in 81 selected counties. (Survey)	Region	1988-91 (phase I), 1991-94 (phase II); data collected once.
National Health Interview Survey (NHIS)	Nationwide household interview survey of non-institutionalized civilians; incidence of acute conditions, hospitalizations, disability days, prevalence of selected chronic conditions and self-reported health status. (Survey)	Census region and SMA	1957-first data collection; completed annually.
National Hospital Discharge Survey (NHDS)	Nationally representative sample data on patients discharged from non-federal short-stay (<30 days) and general hospitals. (Survey)	Census region	1965-first data collection; completed annually.
National Medical Care Utilization and Expenditure Survey (NMCUES)	Data on health, access to and use of medical services, associated charges, payment sources and health insurance coverage for civilian noninstitutionalized population. (Survey)	National	1980-data collection; study completed once.
National Nursing Home Survey (NNHS)	Nationally representative data on characteristics of nursing homes, their services, residents and staff. (Survey)	SMSA	1973-74-first data collection; 1985-most recent data available; completed irregularly ('73-74, '77, '85, '95)

Supplements to the National Health Interview Survey

Cancer Risk Factors Supplement	A national sample of approximately 49,000 (1987) and 24,500 (1992) households. Data includes information about diet, screening practices, tobacco use, occupational exposure, cancer survivorship, medical care, and attitudes/ knowledge about cancer and diet. (Survey)	Region	1987-first data collection; 1992-most recent data available; irregular collection.
Child Health Supplement	Approximately 17,000 children randomly selected from NHIS respondents. Data set includes: household composition, child care, behavioral problems, use of health services, chronic disease presence/impact, accidents, injuries and poisoning. (Survey)	Region	1981 and 1988-data collection; survey completed twice.
Disability Supplement	3-part survey which screens for disability and includes: income and assets; sensory, mobility and communication impairments; functional limitations by ADLs and IADLs; caregivers; mental health; services and benefits; children; and perception of disability. (Survey)	Region (some data by MSA)	1994-95-first data collection; 1st phase could be available in 11/95; planned for once, including 3 phases.
Health Insurance Supplement	Nationwide household interview survey of non-institutionalized civilians; includes detailed HMO/health insurance data, job lock, employment information, out of pocket expenses, denial of application. 1995 will include managed care programs. (Survey)	Region	1963-first data available; 1992-most recent data available; biennial collection as part of the NHIS, and additional surveys irregularly.
Longitudinal Study of Aging I (LSOAI)	Longitudinal study to follow-up cohort from Supplement on Aging. Follow-up interviews done in 1986, 1988 and 1990. (Survey)	Region	1986-1990-data collection; study completed once, including 4 contacts.
Longitudinal Study of Aging II (LSOAII)	Baseline data to be established in supplement to NHIS '94. Nationally representative sample of approximately 10,000 civilian, noninstitutionalized persons 70 years and older. Three follow-up contacts, 2 years apart to begin in 1996. (Survey)	Region	1994-data collection; not yet available; completed once, including 4 contacts.
Supplement on Aging	Established baseline data to study changes in functional status and relationship between social and health factors and death. (Survey)	Region	1984-data collection; study completed once.

Other Than NCHS Data Sets

Annual Person Summary [Health Care Financing Administration (HCFA)]	Five per cent representative sample of aged persons, taken from Medicare bills; and 25 per cent of disabled persons Medicare reimbursed bills. (Survey)	States	1978-first data available; 1985-most recent data available; annual collection.
Area Resource File (ARF) [Health Resources and Services Administration]	A comprehensive file of all facilities in the U.S. with three or more beds that provide medical, nursing, personal or custodial care, including health professions, revenues, health status, mortality and natality, health training programs and socioeconomic and environmental	County	1963-first data available; 1992-most recent data available; ongoing collection.

	characteristics.		
Behavior Risk Factor Surveillance System (BRFSS) [Centers for Disease Control]	State, population-based telephone survey to assess health-related behavioral risk factors associated with the leading causes of premature death and disability. Core questions standardized; states can add questions as needed. Majority of states have ongoing surveillance effort. (Survey)	State (County in 1994)	1982-first 24 states collected data (by 1994 all states participating); data availability varies by state.
Client Data System (CDS) [Office of Applied Studies, SAMHSA]	State reported data on clients or co-dependents in drug and/or alcohol programs for which the provider receives government funding. (Admininistation)	Cities	1990-first data collection (some states); 1993-most recent data available; ongoing collection.
Client Oriented Data Acquisition Process (CODAP) [National Institute on Drug Abuse]	Required reporting from facility admission and discharge records including data on legal/non-legal drugs. (Admininistration)	State	1975-1981 - data collected annually.
Continuous History Disability Sample (CHDS) [SSA]	Twenty per cent annual sample of persons filing for SSA benefits.	Counties	1975-first data available; 1985-most recent data available; annual collection.
Continuous Medicare History Sample File (CMHS) [HCFA]	Five per cent sample of beneficiaries regardless of utilization.	National	1974-first data available; 1985-most recent data available; collected 1974-85.
Current Population Survey (CPS) [Bureau of the Census]	Multi-stage clustered sample of civilian noninstitutionalized population. Dataset includes demographic characteristics and labor force status including occupation, industry, hours worked, duration of unemployment. (Survey)	MSA of 250,000 population and larger	1968-first data collection; 1993-most recent data available; completed monthly.
Epidemiologic Catchment Area (ECA) Program Community Surveys [National Institute of Mental Health]	Complex, multistage, stratified household sample in St. Louis, MO, Baltimore, MD, New Haven, CT, Durham, NC, and Los Angeles, CA. Also included respondents from nursing homes, prisons and mental hospitals. (Survey)	Census tract	1980-first data collection; 1985-most recent data available; 2 waves at 4 of the 5 sites.
Established Populations for Epidemiologic Studies of the Elderly (EPESE) [National Institute on Aging]	Five year longitudinal study of 65 years and older from E. Boston, MA, Iowa and Washington Counties, IO, New Haven, CT, and Durham NC. (Survey)	Household	1982-first data collection; 1987-most recent data available; 5 yr. surveillance, annual contacts.
Healthcare Cost and Utilization Project (HCUP) [Agency for Health Care Policy Research]	Approximately 10 per cent sample (phase I and II) and 20 per cent(phase III) of acute care, non-federal hospitals including data on hospital characteristics, discharge records, physician characteristics and population. (Admininistration)	Zip code	1970-77 (I)-first data collection; 1980-87 (II)-most recent data available; 1988-94 (III)-next planned data collection.
Hispanic Health and Aging Studies -1993 (HHAS) [National Institute on Aging, NIH]	Longitudinal, epidemiological study of non-institutionalized Hispanic men and women 65 years and older. Study compiles rates of specific diseases/disabilities, factors affecting health status, and	Studies in Arizona California Colorado New Mexico	Data collection began in 1993; data not yet available; 2 waves planned, 4-5 years

	health care services utilization	Texas	longitudinal.
Medicare Current Beneficiary Survey (MCBS) [Health Care Financing Administration (HCFA)]	National stratified probability sample of beneficiaries, including non-aged disabled and five cohorts of aged. All cases tracked for 3 years relative to health status and health care utilization	National	1992 most recent data available, although annual releases are planned
Medicaid Statistical File [Health Care Financing Administration]	Summarized data from Form HCFA-2082 including all paid claims; reported by state Medicaid payments, type of eligibility and service, coinsurance, long term care, etc. (Administration)	State	1987-first data collection; 1993-most completed annually.
Medicaid Statistical Information System (MSIS) [Health Care Financing Administration]	Data set contains fewer data elements than the Medicaid Tape-to-Tape, however includes from 25-29 states (varies from year to year). Data currently in process of being validated for research. (Admininistration)	Zip Code	1986-first data collection; 1992-most recent data available; collected quarterly.
Medicaid Tape-to-Tape [Health Care Financing Administration]	Pilot project geared toward providing uniform data for research. Sample includes data from 4-5 states (varies by year). (Administration)	Zip Code	1980-first data collection; 1992-last data collection
Medicare Annual: Person Summary File [Health Care Financing Administration]	Five per cent sample of aged and 25 per cent sample of disabled Medicare population. (Administration)	State	1978-first data collection; 1992-most recent data available; annual data collection.
Medicare Automated Data Retrieval System (MADRS) [Health Care Financing Administration]	All Medicare Part A and B Bill and Payment records. (Admininistration.)	Counties	1984-first data collection; 1991-most recent data available; monthly collection.
Medicare Beneficiary File System [Health Care Financing Administration]	All Medicare claims (bills and payment records) - samples used vary from file to file. (Admininistration)	Zip codes	1984-first data collection; 1991-most recent data available; monthly collection.
Medicare History Sample [Health Care Financing Administration]	Five per cent sample of all Medicare utilization records; longitudinal study by person including: hospital and ECF stays, billing amounts and utilization data. (Admininistration)	County	1974-first data collection; 1993-most recent data available; annual data collection.
Medicare Part B; 5 Percent Sample Bill Summary Records [Health Care Financing Administration]	Five per cent sample of Supplementary Medical Insurance bills to track amount, type, place and cost of health care used.	State	1976-first data available recent data available; ongoing collection.
National Master Facility Inventory (see Area Resource File)			
National Medical Expenditure Survey (NMES) [Agency for Health Care Policy and Research]	National probability sample survey. Includes data on health status, use of health care services, sources of payment, employment, income and demographics. (Survey)	Region	1977-first data collection (NMCES); 1987-most recent data available; completed irregularly, 1996-next planned data

National Outpatient Profile [Commission on Professional National and Hospital Activities]	Medical records from national sample of one million inpatients and 350,000 outpatients in short-stay non-federal hospitals.	Census regions	NA
New Beneficiary Survey (NBS) [Social Security Administration]	Interviews with three types of beneficiaries who began receiving SS benefits in 1980-81: retired workers, persons with disabilities, and wife/ widow beneficiaries. Data includes demographics, marital/childbearing history, employment, income/assets and health. (Survey)	1st wave by SMSA; 2nd wave national	1982-first wave of data collection; 1991-2nd wave of collection.
Survey of Income and Program Participation (SIPP) [Bureau of the Census]	Census-based, nationally representative sample of noninstitutionalized persons. Study designed to measure the economic situation of persons aged 15 and older. Survey looks at types of income received, disability, assets, taxes, and labor force status. (Survey)	County	1983-first data collection; 1991-most recent data available; data collection is ongoing.
Uniform Clinical Data set (UCDS) [Health Care Financing Administration]	A proposed national database for Medicare's quality review program. The data set will include clinical data (1800 variables per generic quality reviews (random five per cent sample of Medicare admissions for problems that are independent of diagnosis), and disease-specific reviews of care to focus on defined clinical conditions (excluding management of patients with acute myocardial infarction).	Hospital service area	To be implemented in 1996

Appendix 1–B: Abstracts of Selected Major Data Sources Reviewed

Dataset and Sponsor	Periodicity	Description	Design and Sample	Geographic Area	Relevant Data Collected
American Housing Survey; HUD	Continuous	Purpose is to provide a current and ongoing series of data on the size, state and composition of the nation's housing and its occupants. The sample includes personal/board and care homes.	Design: Basic national AHS sample is a systematic, unclustered, stratified sample of 61,000 housing units chosen from the 1990 census. There are 44 metropolitan sample areas with a sample size for each metropolitan sample area of 4,250 or 8,500 housing units. The 44 metropolitan areas are covered over a 4 year cycle. Unit of analysis is the household and persons. The survey is conducted every two years. Most current is 1995.	National	Demographic: age, education level, race, ethnicity, sex, marital status, migration/mobility, income/wealth: labor force participation, total income and sources of income. Housing 1) Type of housing: Housing Unit, apt., flat, mobile home, HU in non-transient hotel, HU permanent in transient hotel, HU in rooming house, boat, not specified above / Other Unit (quarters not HU in rooming or boarding house, student quarters in dormitory, other unit not described above). Noninstitutional housing also includes group residences for the aged, handicapped, and disabled. 2) no. and relationship of persons in unit. For 1995, a "Housing Modification Supplement " was included.
Area Resource File; DHHS, Health Resources and Services Administration, Bureau of Health Professions	Ongoing collection	A computerized comprehensive health resources info. system of all facilities in U.S. with 3 or more beds that provide medical, nursing, personal or custodial care to groups of unrelated person on an inpatient basis; 3 Categories: hospitals, nursing/related care homes and other custodial/remedial care facilities.	ARF contains 7000+ variables at the county level. These are derived from a mulitude of resources such as the U.S. Census and annual surveys of hospitals. Many data elements are not updated annually. Among the purposes is a tracking of the number, type and geographic distribution of inpatient facilities.	State and County level; MSAs and SMSAs	Demographic: age, education level, race, ethnicity, sex, marital status, migration/mobility. Vital Statistics: natality, mortality, marriage and divorce. Housing: 1)Types of housing: Housing Unit: apt., flat, mobile home, HU in non-transient hotel, HU permanent in transient hotel, HU in rooming house, boat, not specified above / Other Unit (quarters not HU in rooming or boarding house, student quarters in dormitory, other unit not described above) 2) no. and relationship of persons in unit. Income/Wealth: labor force participation, total income and sources of income. Information on health facilities, health professionals, health care expenditures, and vital statistics.

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Dataset and Sponsor	Periodicity	Description	Design and Sample	Geographic Area	Relevant Data Collected
Behavior Risk Factor Surveillance System; BRFSS/CDC	Most recent available 1992; Monthly collection	Purpose is to assess the prevalence of health related behavioral risk factors that are associated with the leading causes of premature death and disability; Can link to the NHIS	A national, population based telephone survey; Total BRFSS has appx. 90,000-100,000 respondents per year; Note: In 1994, 8 states did the activity limitation module (approximately 10,000 respondents)	Smallest geographic area: State; county to be available in 1994	In the core questionnaire are questions on self-assessed physical status
Continuous Disability History Sample; Office of Disability, Social Security Administration	Annual collection	To support special studies of the disability applicant population (SSDI)	Population surveyed: A 20 per cent annual random sample of persons filing for SSA benefits, stratified by state; Data Source: Bureau of Disability Insurance's Disabled Data Record File (Persons applying for disability benefits under the social security disability program (Title II) and for whom eligibility determinations have been made); the sample is linked to the Master Beneficiary Record and Summary Earnings Record	Largest geographic area: National Smallest geographic area: State	Demographic: age, sex, race, occupation, annual earnings, employment status, family composition (children) Housing: Rural/Urban residence Agency Related: agency decision, allowance/denial, legal basis, medical diag.; onset day, payment history, worker/family payments, reason for termination Disability / Health Status: acute/chronic conditions, disability days, impairments of usual activity status, duration of disability, mobility
Decennial Census of Population and Housing	latest 1990	Information collected describes the basic demographic and housing characteristics of the United States population. Included among the many tabulations and tape files is a summary statistics file representing a 100 per cent count of persons in "group" quarters. Group quarters include persons in institutions and noninstitution having five or more unrelated persons.	Civilian non-institutional population in the United States living in housing units and members of the armed forces in civilian housing units on a military base or in a household not on a military base. Data is based on a 100 per cent enumeration of the population.	Largest unit: National Smallest unit: Block, Census Tracts, and Zip Code Areas	Demographic: age, education level, race, ethnicity, sex, marital status, migration/mobility Housing: 1) Type of dwelling, (mobile home, trailer, house, apartment, group housing). No specification that disaggregates group housing into subtypes like residential care. 2) Number and relationships of persons in household Income/Wealth: Labor force participation, total income and sources of income Disability/ Health Status: work disability, mobility limitation, self-care (ADL) limitation

Dataset and Sponsor	Periodicity	Description	Design and Sample	Geographic Area	Relevant Data Collected
Epidemiologic Catchment Area; NIMH/DHHS	1985 most recent data available	Purpose is to assess the prevalence and incidence of mental illness and mental health services use in five different sites in the United States.	Complex, multistage, stratified household sample in St. Louis, MO, Baltimore, MD, New Haven, CT, Durham, NC and Los Angeles, CA. Survey also included respondents from nursing homes, prisons and mental hospitals; Response rate: 75-80 per cent per site.	Smallest geog. area: Sample community	Demographics: education level, race, ethnicity, sex, marital status, migration/mobility Housing: 1) Type is noninstitutional 2) Number of persons in household Income/Wealth: labor force participation, total income, sources of income Health and and Mental Health: Cognitive Impairment, behavior problems, depression, and alcohol/drug use, changes in health status, morbidity Health Care Utilization: general hospital, nursing home and mental health services; alcohol/drug abuse; physician services, etc.

Dataset and Sponsor	Periodicity	Description	Design and Sample	Geographic Area	Relevant Data Collected
Medicare Current Beneficiary Survey (MCBS); Health Care Financing Administration (HCFA)	1992 most recent data available	The MCBS is an ongoing, multipurpose survey of Medicare beneficiaries. The survey provides the information needed to monitor changes in the Medicare program and provide basic information for the estimation of health care costs and utilization. (It replaces the Current Medicare Survey, which had been conducted by the Social Security Administration.) The MCBS includes both community and institutional populations. These are selected proportionate to their distribution among all eligible beneficiaries. For this reason, the members of these subgroups have to be pooled across periods to obtain reliable statistical estimates. To date, there has been only one survey round with a supplemental interview--in this case those receiving home health care. Living arrangement data are collected for both those in the community and those living in institutions.	The sample is derived from a collection of 107 Primary Sampling Units (consisting of metropolitan areas and clusters of non-metropolitan counties). Separate strata are compiled for the disabled under age 65, and for five cohorts of persons over the age of 64. The strata are of equal size (n is approximately 2,000 per strata), producing a total baseline sample of about 12,000 persons. All cases receive an initial interview, and a reinterview every four months through to a total of 12 interviews or 36 months of tracking. The original panel was first interviewed in 1991; since 1994 there has been a phased supplemental sample of new beneficiaries. Phasing is designed to replace one-third of the panel annually, thus assuring maintenance of a longitudinal panel, and an ample sample for cross sectional analyses. Response rates for the inital interview are just over 87 percent, and average 98 percent for the subsequent rounds of interviews. All data is collected via personal in-home (or institution) interview.	Sampling is designed to provide national estimates of Medicare enrollees. While the survey includes a representative sample of those dually eligible for Medicare and Medicaid, it is not designed to produce Medicaid cost estimates. Generalizations can be made to metropolitan and non-metropolitan populations only.	Included in the survey is information on the pattern of insurance coverage, types of physician or specialists providing care, setting in which care is provided (e.g., inpatient, nursing home, community setting), prescribed medications, beneficiary perceptions of the Medicare program, satisfaction with the care received, health conditions, functional status, and living arrangements. Survey data are linked with Medicare administrative billing records, and death records.

Dataset and Sponsor	Periodicity	Description	Design and Sample	Geographic Area	Relevant Data Collected
National Health Interview Survey; NCHS/DHHS	1994 most recent data available; annual data collection	Nationwide household survey of civilian, non-institutionalized population; Purpose is to provide data on the prevalence of acute conditions, limitations of activity, persons injured, hospitalizations, disability days, physician and dental visits and prevalence of selected chronic conditions. For 1987, linkage with NMES and National Family Growth Survey. Each wave of the survey includes supplemental surveys. In 1994-95 the supplement was for the Disabled population. That data is expected in 1996.	A probability sample of 36,000-47,000 households (with 92,000-125,000 persons) is interviewed annually; The core is not longitudinal; All counties are examined and similar counties are grouped together and total of 198 Primary Sampling Units are selected; Some sample units include special living arrangements (dorms, institutions, convents, mobile home parks.)	Largest Area: National Smallest Unit: region, and metropolitan/rural area aggregations	Demographic: age, education level, race, ethnicity, sex marital status Housing: 1) Type of dwelling 2) Number and relationships of persons in household? Income/wealth; labor force participation, total income Health status/disability: Self reported; acute/chronic conditions disability days, chronic limitations of activity and mobility, sensory and functional impairments; limitations in ADLs; mental retardation and developmental disabilities; physical, emotional and cognitive impairments; use of and need for various devices and services; transportation, housing and employment barriers and difficulties; use of special education programs and impact of disability on family
National Long-Term Care Survey; DHHS, Agency for Health Care Policy Research and the National Institute on Aging	1982, 1984, 1987	This is a longitudinal survey of elderly persons at risk of or already experiencing chronic impairments, as measured by activities of daily living or instrumental activities of daily living. Data include both personal attributes and the attributes of their primary informal caregiver	Target population: individucals +65 who are functionally limited; Sample size: 20,000. The initial sample includes only persons in the community, but subsequent waves track and interview persons who enter institutions.	Largest Area: National	Demographic: age, sex, race, ethnicity, education. Informal caregiver assistance Housing: 1) Type of dwelling: housing unit, other unit, unit in a special place 2) Number and relationship of persons in household, neighborhood characteristics 3) Placement in institutions, and facility characteristics Financial: Income/Wealth, health insurance Health Status: Chronic limitations of activity/mobility, medical conditions, cognitive functioning Health Care Utilization: Medicare hospital, Physician, and other covered services/visits, prescription drug use, and dental visits

Dataset and Sponsor	Periodicity	Description	Design and Sample	Geographic Area	Relevant Data Collected
National Medical Expenditure Survey, Household Survey I, Population and Home Health Providers; AHCPR	1987	To provide a comprehensive statistical picture of how health services are used and paid for in the U.S.	Survey of approximately 14,000 households; Universe: civilian, non-institutionalized population of the U.S. living in housing units, group quarters and non-group quarters Sampling: stratified, multistage area probability sample of dwelling units including oversamples of African-Americans, Hispanics, the elderly, the functionally imparied and the poor Unity of analysis: persons (members of dwelling units and home health providers) and household	Largest Area: National	Demographic: age, sex, race, ethnicity, marital, student and veteran status, employment status Housing: 1) Type (housing unit, group quarters and non-group quarters) 2) Number in household Financial information: Health insurance including Medicare/Medicaid coverage, income and assets Health Related: Health status and health conditions, functional status (ADLs/IADLs), type of help required, health care service use.
National Nursing Home Survey (NNHS); NCHS	1987; Latest phase is expected to be available in 1996	Purpose is to collect data on nursing homes, services, staffing and financial characteristics and on personal and health characteristics of residents and discharges	Data collected from a representative sample of all nursing homes in the coterminous U.S.; Samples in each nursing home are selected of current residents, person discharged and staff members; The target pop. are persons in nursing homes of all ages; Sample size: 2000 facilities and 12,000 residents. Universe: facilities, nursing and related care home and residents and institutionalized persons. The sample frame is the Masters Facilities Inventory. Stratification is by type of ownership, size, and type of care	Largest geog. unit: National Smallest geographic unit: DHHS Regions	Facility: size, ownership, Medicare and Medicaid certification, staffing patterns and services offered and finances Residents: 1) Demographics: education, race, ethnicity, sex, marital status and migration/mobility, living arrangements prior to admission 2) Health-Related: diagnosed conditions, functional status, receipt of services (medical, nursing and therapeutic), cost of care, source of payment, health and functional status prior to nursing home admission, lifetime use of nursing home care and Medicaid Spend Down 3) Health expenses: Costs of care out of pocket costs, Medicare and Medicaid Expenditures, Private Insurance 4) Next of Kin: Information about residents 5)Discharges: living arrangements

Dataset and Sponsor	Periodicity	Description	Design and Sample	Geographic Area	Relevant Data Collected
New Beneficiary Survey; Social Security Administration	1987 1st wave (SMSA); 1991 2nd wave	Objective is to provide longitudinal data on the dynamics of disability and aging. The survey does not identify the disability that qualifies a respondent for benefits, it only records self reported conditions and activity limitations.	Personal interviews with a random sample of non-institutionalized U.S. Social Security beneficiaries and their spouses; Survey population: Title II workers with disabilities receiving SSA benefits; Size of sample 13,962 (12,128 original sample persons and 1,834 widows/widowers of original sample persons). Unit of analysis: individual	National	Demographic: gender, age, race/ethnicity, marital status, educ. level, household composition, vital status of parents and children of respondents Housing: 1) Type: trailer, apartment, housing unit, school/govt. building, other. 2) Number and relationship of person in household Employment/Income: employment history, sources of monthly income, pensions and lump sum payments, assets, debt, salary, marital change and its economic effect on health care coverage, Medicare charge for services Health Related: self-reported health conditions, disability days, health conditions limiting ability to do paid work, limitations of activities in ADL/IADLs Other: annual history of covered earnings and SSA benefits; reasons for not working; date started.
Survey of Income and Program Participation (SIPP); Bureau of the Census	1984-1990 panels	Objective is to measure the economic situation of persons aged 15 and older. Survey looks at type of income received, disability, assets, taxes, and labor force participation. Will also provide the number and characteristics of persons with disabilities and will provide a baseline for future assessment	Longitudinal, nationally representative Universe: the resident, civilian, non-institutionalized population of U.S. Sampling: multistage stratified design selecting appx. 26,000 housing units of which 21,000 were eligible for interview. 5,500 households are interviewed each month and then re interviewed at 4 month intervals. All persons at least 15 years old present as household members at the first interview are followed for a total of nine waves in each panel	Largest Area: National Smallest Area: County and Region	Demographic: age, sex, race/ethnicity, Hispanic origin, monthly earnings, occupation and educational status marital status Housing: 1) Type of dwelling 2) Number and relationship of person in household Income/Wealth: Labor force participation, total income, source of income and net assets; whether receiving public benefits; monthly amount paid for help Health Expenses: Costs of care, out of packet costs, Medicare/Aid, and private insurance Health Related: chronic limitations of activity and mobility, impairment, usual activity status; ADLs and IADLs; existence of specific conditions; use of special aids Health Care Utilization: General hospital services; Healthcare in home by non-profit organization; Identify caregiver, length of time help is needed

77

78

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